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ABSTRACTS BOOK



Patient pathways - Brain health and prevention

P01. Brain health and prevention

P01-01Universal prevention of dementia in Italy: a document analysis of the 21 Italian regional prevention plans

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Introduction: Interventions targeting 12 modifiable risk factors (RFs) at different stages of life can potentially prevent approximately 40% of dementia cases. To achieve maximum effectiveness, individual-based interventions that focus on high-risk individuals should be combined with population-based interventions that address the accessibility to and penetrance of RF. We analysed the different subnational population approaches that Italian regions have implemented to prevent dementia.
Methods: We conducted a document analysis of the 21 Regional Prevention Plans (RPPs) for 2020-2025. We categorised the dementia-specific preventive interventions according to (i) the type of RF targeted, (ii) the target age, and (iii) the target population. Indirect potential beneficial effects of interventions were defined by reviewing published literature on plausible relationships between RFs. Furthermore, we developed and applied to all RPPs a checklist evaluating key elements of situational analysis and prevention planning.
Results: Physical inactivity was the only RF covered by all RPPs, as a direct target of

117/248 interventions for dementia prevention. Smoking was targeted in more than 50% of RPPs, while less than 50% covered alcohol consumption and obesity. Only 25% of RPPs had dementia-specific interventions for social isolation, hypertension, and diabetes. Two RPPs targeted air pollution and only one traumatic brain injury (TBI). No RPP directly covered low education, depression or hearing loss for dementia prevention. The total scores on the checklist ranged from a minimum score of 7 to a maximum of 28/63, showing a recurrent lack of information on the burden of disease as well as on the feasibility of interventions.
Conclusions: The prevalence of interventions focused on cardiovascular RFs may suggest that policymakers are not fully aware of RFs more specific to dementia (e.g., TBI and hearing loss). The lack of dementia-specific situational analyses may hinder the implementation of the interventions. A dedicated tool may facilitate programming and transnational communication.

Patient pathways - Brain health and prevention

P01. Brain health and prevention

P01-02Effects of a multidomain lifestyle intervention on dementia risk profiles – focus on nutrition

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Background: Multidomain lifestyle interventions constitute a promising strategy to reduce risk for dementia on a scalable level. However, changes in cognitive performance or incident cases of dementia are difficult to observe, as they require extensive follow-up periods. Changes in dementia risk profiles and lifestyle have been suggested promising surrogate outcomes for lifestyle interventions against cognitive decline and dementia. Methods: Using data from the cluster-randomized multidomain AgeWell.de-trial, we will present analyses on 1) intervention effects on dementia risk profiles, assessed using the Lifestyle for Brain Health (LIBRA)-index; 2) determinants of a healthy diet; 3) intervention effects on participants' nutrition. AgeWell.de was conducted in older primary care patients at increased risk for dementia (age: 60-77 years, n(baseline): 1.030) in Germany. The multidomain intervention comprised optimization of nutrition and medication, enhancement of physical, social and cognitive activity and was conducted over 24 months. Results: The intervention reduced LIBRA-scores, indicating reduced risk for dementia at follow-up (b=-0.63, 95%CI: -1.14, -0.12). Intervention effects were particularly due to improvements in diet and hypertension. However, several risk factors, e.g., physical inactivity, were not amendable to change. Adherence to a healthy diet, assessed using a composite score (range: 0-11 points), was moderate at baseline (M = 4.2). Female sex, higher levels of motivation for healthy eating, and higher self-efficacy were linked to better adherence. The intervention improved participants' diet, assessed using the total score (b=0.06, IRR: 1.06, 95% CI: 1.01, 1.11). Changes were particularly due to increased consumption of fruit and vegetables at follow-up. Discussion: A multidomain lifestyle intervention can improve participants' dementia risk profiles. This was particularly due to favorable changes in diet. Future interventions should be tailored to individuals' current stage of behavior change and level of self-efficacy. Including specific intervention components to strengthen motivation and self-efficacy might increase intervention effectiveness.

Patient pathways - Brain health and prevention

P01. Brain health and prevention

P01-03Assessing potential for dementia risk reduction in low and middle-income countries: findings from the WHO study on global ageing and adult health (SAGE)

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Objectives: In the expected global surge of people living with dementia, low- and middle-income countries (LMICs) will be disproportionally represented. Epidemiological studies support the possibility of dementia risk reduction by lifestyle modification. However, estimates for preventative potential are mainly based on samples from high-income countries. Therefore, the current study aimed to assess the prevalence of modifiable dementia risk factors in LMICs and estimate the number of dementia cases associated with them. Methods: We used data of 20,814 people aged 60 years and older, from six LMICs (China, India, the Russian Federation, Ghana, Mexico, and South Africa) participating in the World Health Organization's (WHO) Global Study for Ageing and Adult Health (SAGE). Prevalences of eleven modifiable dementia risk factors (low education, depression, hypertension, diabetes, unhealthy diet, obesity, physical inactivity, smoking, daytime sleepiness, low social activity engagement and loneliness) were estimated following established guidelines and validated cut-offs. Population attributable fractions were then calculated, using relative risks derived from existing meta-analyses and adjusting for risk factor communality. Results: Participants were on average 69.9 years (SD=7.61) and 54.7% were female. Across countries, the prevalence of modifiable dementia risk factors ranged from 9.53% for diabetes to 55.6% for unhealthy diet. Between-country heterogeneity of risk factor prevalence was high for all factors considered. Relatedly, there was substantial diversity in population attributable fractions, with the highest preventative potential being present in the Mexican dataset. Conclusion: A substantial number of dementia cases in LMICs may be associated with potentially modifiable risk and protective factors. Our estimates suggest that the potential for risk modification is higher than those previously reported based on high-income countries. We provide an in-depth analysis of the most beneficial targets for dementia risk reduction in policy and practice in LMICs.

Patient pathways - Brain health and prevention

P01. Brain health and prevention

P01-04A cross-sectional study on the association between residential noise exposure, cognitive functioning, and structural markers of brain damage - the Maastricht study

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Background: Environmental noise exposure is negatively associated with physical health and mental health through different pathways. Given the heterogeneous findings in previous studies, it is crucial to further investigate into how environmental noise exposure affects both brain health and cognitive function. Therefore, this study tests the association of residential noise exposure with cognitive functioning and markers of brain damage in a large sample of the adult general population. The investigation incorporates an examination of various dementia risk factors and demographic variables to ensure comprehensive analysis. Methods: Cross-sectional data (cognitive functioning and brain volumes of MRI-markers) from 4,018 Dutch participants aged 40-75 years from The Maastricht Study were matched to residential noise exposure data (including noise from roads, railways, aviation, industry, and wind turbines) available at home address-levels provided by the Geoscience and Health Cohort Consortium. Linear relationships were investigated in multiple regression analyses and non-linear associations were tested by restricted cubic splines, adjusted for demographic and lifestyle factors. Results: Higher residential noise was associated with lower white matter (WM) volume and higher cerebrospinal fluid (CSF) volume (more atrophy). Non-linear associations were found between higher residential noise in the low to mid-range and lower grey matter (GM) volume. This was inverted with higher residential noise in the mid-to-high range being associated with higher GM volume. Residential noise was not associated with cognitive functioning. Discussion/Conclusion: Our findings showed that higher residential noise was associated with markers of brain atrophy (lower WM and higher CSF volumes), while results for GM were counterintuitive. Future research is needed to further investigate additional factors such as individual housing quality and isolation, regional protective measures against noise and subjective noise experience, and potential damaging threshold effects of noise exposure. Keywords: Cognition, MRI, brain damage, noise, dementia risk factors, epidemiology, cohort study;

Patient pathways - Brain health and prevention

P01. Brain health and prevention

P01-05Successful implementation of prevention research results through a patient organization

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Introduction: Implementation of research findings remains a significant challenge worldwide. National Alzheimer organizations possess expertise in reaching large populations through their own platforms and have marketing and communication skills. At the same time, scientists can have insights in the field of dementia which are lacking at the Alzheimer organizations. By combining forces, we can improve our communication to the lay public. Alzheimer Nederland and the Alzheimer Center Limburg worked together to improve an existing e-learning on dementia risk reduction. Methods: A multidisciplinary team comprising of scientists, science editors, and marketing specialists collaborated to enhance the existing e-learning. Drawing input from participant evaluations, analysis of most viewed elements, and the latest scientific insights, we optimized and extended the content. The popular quizzes became the focus of the e-learning, now enriched with additional information. Engaging videos and easily comprehensible text with visuals were strategically integrated to encourage exploration of further content. The effectiveness of the training was assessed through a pre-post survey study conducted by Van Asbroeck et al (see abstract Van Asbroeck). Result: An integrated evidenced-based e-learning on dementia risk reduction was successfully updated to provide better content to the lay public. The collaboration between research and practice yielded several synergistic benefits: 1. Rapid participant recruitment. Organic traffic on the website facilitated the enrollment of all the required 477 participants within 6 weeks, obviating the need for additional advertising campaigns. 2. Automatic implementation. Within the initial three months of deployment, 22.000 participants registered for the e-learning. Based on past participations rates, we anticipate a minimum of 40.000 participants completing the training annually. Conclusion: Collaboration between researchers and Alzheimer organizations or other stakeholders holds high potential for the effective implementation of scientific results. Close partnership leads to substantial benefits, including accelerated research, smoother implementation and immediate utilization of research findings.

Living with dementia - People living with dementia

P02. People living with dementia

P02-01Our marriage with dementia

Chris Roberts, Jayne Goodrick

I am Chris Roberts and I received a dementia diagnosis 12 years ago. I am currently the Chair of the Alzheimer Europe European Working Group of People with Dementia and I am also co-founder and member of the 3Nations Dementia Working Group (3NDWG, England, Wales and North Ireland).
In this presentation, my wife and supporter, Jayne Goodrick, and I will talk about where we were at the time we received the dementia diagnosis, how that left us feeling and how we picked ourselves up to live with this new life, this life with dementia. We will also talk about how we adapted to this diagnosis, the importance of swapping roles and the effects that dementia has on our family as a whole.
We will also tell you how we created that new life of which awareness and advocacy became a very important part and through which we have achieved a lot in this last decade I have been living with dementia.
In the final part of our presentation, we will tell you how the dementia has progressed, how we keep on adapting and changing our life around it, and where we hope to go next on this constantly changing journey.

Living with dementia - People living with dementia

P02. People living with dementia

P02-02My lifestyle before Alzheimer disease and now

Věra Ryšavá
Česká alzheimerovská společnost, o.p.s.

Věra will be talking about her life before diagnosis and her normal life with Alzheimer disease. Instead of despair and depression she chooses to invest her time and energy to getting information about healthy lifestyle and interventions that keep her happy and

confident. She continues contributing to the work of the Czech Alzheimer Society, speaks at public and support her new friends with dementia during self-support groups.

Living with dementia - People living with dementia

P02. People living with dementia

P02-03Living with dementia – Living my best life

Margaret McCallion

Many challenges have been faced throughout my life, receiving a diagnosis of dementia at the age of fifty-one has been the biggest.
My name is Margaret McCallion, I'm from Glasgow Scotland, and I'm living my best life.
I was working with the National Health Service within the administration in my hometown when I started to experience issues with my abilities at work. After various appointments and medical tests, I was diagnosed with a rare type of dementia, Frontal Temporal Dementia.
My Life then changed, and I went through every emotion possible.
My employer ended my employment, and for the first time in my life, I had to get financial support from the Government. I wasn't of pension age, I was unemployed.
The next few months were challenging: coming to terms with my diagnosis, sorting out the local bureaucracy systems and the benefits system. It all made me feel like I was worthless.
Reaching out to the local Alzheimer Scotland association was a decision that changed my life. Finding people who understand, who can help and give advice, and who are going through the same, gave me new opportunities, a sense of Identity and self-worth.
I have great family support and still meet up with old friends/colleagues, I sing, I act, I dance, and I challenge the stigma and inequalities faced by people like me every day through my active membership of the Scottish and European Dementia Working Group. I want to make things better for the next people. I don't want people like me to be written off, I want to be seen as the person, Margaret, not the dementia diagnosis.
My experiences instilled in me a passion to change things for the better.
This May, I reach another milestone celebrating my 60th birthday.
I am Living My Best Life.

Living with dementia - People living with dementia

P02. People living with dementia

P02-04I embrace my dementia “for better and worse”

Pia Knudsen
EWGPWD

My name is Pia and I have been living with dementia for the last 4 years. In my speech I would refer to the “better and worse” about living with dementia. Some of the examples of the “worse” include being fired when I received the diagnosis, being left by my partner and experiencing that some “experts” took over on my life. But, dementia also gave me so many presents, including new friendships and influential people who listen to me and helped me be an spokesperson for other people with dementia. The biggest of all I met the love of my life. I spread my voice wherever is possible and I do so for everyone with dementia who doesn’t dare to.

Living with dementia - People living with dementia

P02. People living with dementia

P02-05How getting my hearing checked changed my life

Kevin Quaid[1], Kevin Quaid[2]
[1]Alzheimer Europe, [2]

I am Kevin Quaid, I am 60 years old and have been diagnosed with Parkinson's for 10 years and Lewy Body Dementia for nearly eight years. I am currently Vice-Chair of the European Working Group of People with Dementia (EWGPWD). In this presentation, I will talk about the importance of addressing hearing loss in the context of dementia and how it has personally changed my life.
One of the most distressing parts of having Lewy body dementia is nightmares, fear, paranoia and REM sleep behaviour disorder. I used to wake in the middle of the night from

frightening nightmares and not know who I was or where I was, sometimes so afraid that I would just lay there and cry.
I got my hearing checked and discovered that my hearing was in a pretty bad way. Even though I knew that my hearing was not good it was something that I had ever bothered with because it was fading away slowly. But I found myself withdrawing from conversations and family gatherings.
I hadn't for a moment connected my dementia to my hearing but the connection is unbelievable. I got my hearing sorted and my life has changed, I no longer shy away from conversations or crowds, the noise that used to be in my head when in a quiet room is gone and the frequency and severity of my nightmares have been reduced by at least 75%.
In summary, this presentation will highlight the importance of addressing hearing loss in people who are over 40. Drawing from my personal experience, I will explain how addressing hearing loss can help some people with dementia with their quality of life. I will also highlight the relevance of managing hearing problems for reducing dementia risk in the general population.

P03. INTERDEM Academy

P03. INTERDEM Academy

P03It's not all about the money – tips and tricks to get your research ideas funded

Fania Dassen[1], Frans Verhey[1], Sara Laureen Bartels[1], Esther Loseto-Gerritzen[2], Caitlin Hibbs[1], Golnaz Atefi[1], Hannah Christie[3], Sebastian Köhler[1], Alys Griffiths[4]
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This interactive session with a focus on early career dementia researchers (ECDRs), addresses the topic of funding and networking for grant writing. Being awarded a big research grant is a career milestone for a researcher. But where do you even start as a PhD-student or starting post-doc? For instance, how do you find out about options for funding, how should you actually start writing your proposal, and how do you choose which type of funding to go for? Which networking skills are essential to approach experts in the field to refine your idea and make it "fundable", and which experiences are essential to highlight in your CV? And how does it work when you want to get involved or even become a co-applicant in a bigger international collaboration? The competition is tough and even the

most brilliant and well-written proposals might get rejected. You need a lot of perseverance to succeed in academia, and writing a successful application requires polish and politics.

A recent article on ECDR needs (Dupont et al., 2024) suggests that sharing experiences and opportunities for grant writing with other researchers could be of help. Also, there is a need to learn about funding possibilities nationally and internationally. Therefore, in this session, fellow ECDRs will share their experience with recent (funded and not-funded) grant applications. Senior researchers will share about their "brilliant failures" and lessons learned, as for every successful application, there have been many rejections. As an experienced reviewer, they will also share what they are looking for and value in a grant application. In the end, there will be time for discussion and to share your own experiences and tips and tricks.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P04. Intellectual disability and Down syndrome I

P04-01Inclusion strategies for adults with down syndrome and access to new Alzheimer's anti-amyloid DMTs

Matthew Janicki[1], Hampus Hillerstrom[2], Richard Fisher[2]
[1]National Task Group / ID & Dementia Practices, [2]Lumind IDSC Foundation

The earlier presence of dementia stemming from Alzheimer's disease (AD) in adults with Down syndrome (DS) has been an ongoing concern. The average age of onset of DS-AD dementia is about age 52 and more than 60% of adults with DS show signs of Alzheimer's disease by age 60. The recent approval in some countries of anti-amyloid disease-modifying therapeutics (DMTs), such as Leqembi, for treating adults with early-stage sporadic AD has raised hopes within the DS community. However, it has also raised concerns about the possible exclusion of adults with DS and other intellectual disabilities (ID) due to wording exclusions or vagueness of prescribing criteria and required use of measures that may not apply to people with DS/ID. Efforts have been undertaken in the USA to mitigate prescribing issues and to recommend alternative assessment instruments. An international expert panel was convened and addressed these two potential barriers. The panel recommended alternative prescribing language to permit inclusion of adults with DS specifically and identified diagnostic and impairment assessment instrument

equivalences. Prescribing criteria recommendations include lowering the age of eligibility (<50), using specialized alternative measures for diagnosis and neurocognitive decline relevant to DS/ID, broadening latitude in impairment presentation due to lifelong cognitive limitations (i.e., recognizing behavioral variants), and raising clinician proficiencies in diagnosing dementia in adults with DS/ID (via continuing education). As many adults with DS show younger-age dementia onset and floor effects on typically used AD-diagnostic assessments for adults with sporadic AD this tends to make them less applicable. It is expected that these modifications will enable equitable access to the new medications once they are approved in various countries and concerns about safety are assuaged. Lessons learned from the USA experience can provide valuable insights in how manage these issues in other countries as these AD DMTs are approved.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P04. Intellectual disability and Down syndrome I

P04-02Long-stay dementia care in people with intellectual disabilities: comprehensive review of psychosocial support methods used in The Netherlands

Irene Ijpma, Aurora Ulgiati, Alain Dekker
Alliade

Psychosocial support methods (PSM) help to tackle social, health and psychological challenges faced by people with intellectual disabilities and their caregivers involved in long-stay dementia care.
However, clinical services face a dilemma about which PSM to chose and introduce in clinical practice because of a lack of information, insufficient evidence and inconsistency in findings between different studies. A comprehensive overview of PSM for people with intellectual disabilities and dementia was lacking. This study aimed to provide such a summary of available PSM and their evidence for effect in daily practice.
Specifically, this study addressed the following questions: 1) what defines PSM?, 2) which PSM are available in Dutch intellectual disability care, and 3) what are the elements and characteristics of these PSM (e.g. efficacy, suitability)?
Results showed that a careful and coherent definition of PSM was missing. Therefore, we

provide a clear definition to standardize terminology in healthcare, enabling appropriate comparisons.
After searching for academic publications in three databases (EBSCO, Scopus, and PubMed) and non-academic publications in the Dutch grey literature, 28 interventions were labelled as PSM and included in this study. Three PSM specifically target people with intellectual disabilities and dementia: Dementia Care Mapping, Integrated Emotion-Oriented Care and Urlings-Van der Linden.
PSM converge in giving great relevance to personalized care. However, there is a long way to go regarding evidence for (long-term) efficacy. Dementia Care Mapping showed the best results with regards of efficacy (qualitative + quantitative studies) and suitability.
This study provides an in-depth analysis and synthesis of the body of knowledge about PSM studied among people with intellectual disabilities and dementia. As such, it has important implications for these individuals, professional caregivers, family members and healthcare organizations.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P04. Intellectual disability and Down syndrome I

P04-03A more inclusive Star Branded dementia care – for persons living with an intellectual disability

Ann-Christin Kärrman, Christina Nemell
Svenskt Demenscentrum

The Swedish Dementia Centre (SDC) have previously launched a model called Star Branded dementia care for staff in elderly care.
Staff working with people with intellectual disabilities (ID) has a great need of more knowledge about ageing and dementia and has therefore asked for this model adapted for their target group.
Star Branded is a four-step educational model in accordance with the Swedish National Board of Health and Welfare's national guidelines for dementia. It is available for group housing and service housing. The aim is to give care workers knowledge and tools to enhance person-centred care and knowledge about ageing and dementia for persons with ID. The four steps include web-based courses and four half days with time for reflection. One step includes Early signs, which is a mapping tool for detection of changes in a person's function and abilities that can be a sign of dementia. SDC's Vision Zero – for a dementia

care without restraints is another part of the model.
The education is workplace based, led by experienced co-workers (Star Instructors) trained by SDC.
For a unit to become Star Branded, at least 80% of the co-workers, and all leaders, need to participate in all steps to receive a diploma. The diploma is valid one year, and to keep the star the unit need to do a yearly follow-up to show they follow the criteria.
A pilot was conducted 2023 and was evaluated March 2024. The evaluation showed that 90% thought they had gained a lot of new useful and practical knowledge.
During 2024, we are training Star instructors free of charge with funds from The Ministry of Health and Social Affairs. We have now over 100 registered for the Star instructor training.
Our hope is that this Star Branded model will be as successful as the original.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P04. Intellectual disability and Down syndrome I

P04-04“DIMA”: an innovative experience for a real consideration for people with intellectual disability and dementia in France

Muriel Delporte[1], Federico Palermiti[2]
[1]IRTS, [2]France Alzheimer 06

As life expectancy increases, people with intellectual disability may now be concerned by dementia. In France, this question takes shape in a specific context: public policies divide disability from old age. Support professionals are trained either in disability or dementia, and specialized facilities for people with dementia are often not accessible to disabled people, due to administrative barriers (based on age criteria in particular). Moreover, this issue is still in its infancy, and little attention is paid to it: in France today, it is still difficult to imagine that a person with an intellectual disability could be concerned by dementia.

In this communication, we would like to present an innovative experience called DIMA (Intellectual Disability and Alzheimer's Disease). DIMA is a research community which brings together researchers from different disciplines, professionals in the fields of disability, old age, training, health, families concerned, people with intellectual disabilities and students. Together, we intend to develop appropriate support for people with intellectual disability who are concerned by dementia, either for themselves or for a loved one. DIMA focuses on three main dimensions. First, offering its members a place where they can meet,

exchange ideas, and share experiences. Secondly, building communication tools (website, podcast, …) to disseminate the knowledge identified and produced by the community. Last, informing public policy makers on the measures to be taken in response to this emerging issue. All three axes serve the same objective: ensure that people with intellectual disability concerned by dementia finally receive the support they deserve.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P04. Intellectual disability and Down syndrome I

P04-05I don't know what's going on with Karl. Educational program for colleagues and housemates of people with Down syndrome and dementia

Christina Kuhn, Anja Rutenkröger
Demenz Support Stuttgart gGmbH

People with Down's syndrome have a high risk of dementia. Conflicts often arise at work an in the living space when the behavior of people with Down‘s syndrome is not understood in the context of dementia. Care staff do not feel up to the challenges and a change in the working and living situation is driven forward. Often not to the benefit of those affected. The educational programme provides care staff with the necessary background knowledge on the subject of dementia and also raises awareness among work colleagues and housemates. This results in a better understanding with more diverse support options and courses of action for everyone in the environment. The presentation will outline a project that involves everyone (relatives, caregivers, housemates and work colleagues) in the educational program. In particular, the methodical implementation of how people with Down's syndrome and other learning difficulties can be taught about dementia will be discussed.

P5. LETHE

P05. How technology and Artificial Intelligence can contribute to personalised risk reduction and prevention in dementia: learnings from the Lethe project

P05-01Risk reduction and precision prevention of dementia via multidomain interventions

Francesca Mangialasche
Karolinska Institutet

Dementia risk reduction is pivotal to curb the rapid growth of this disorder. Given the multifactorial aetiology of late-life dementia, multidomain interventions simultaneously targeting several risk factors are needed for effective prevention. The World-Wide FINGERS (WW-FINGERS, 65+ countries) network of multidomain intervention trials for dementia risk reduction and prevention aims to identify effective and sustainable preventative strategies, based on multidomain interventions, building on the seminal Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER). FINGER reported beneficial effects on cognition and other health-related measures of a two-year multidomain intervention in older adults, which included exercise, healthy diet, cognitive training, social stimulation, management of cardiometabolic risk factors. WW-FINGERS works to adapt, evolve, and test the FINGER model in different populations and settings, with innovative multidomain models including pharmacological and non-pharmacological components, and digital solutions supporting intervention personalization. An overview of the WW-FINGERS scientific pillars and activities will be presented.

P5. LETHE

P05. How technology and Artificial Intelligence can contribute to personalised risk reduction and prevention in dementia: learnings from the Lethe project

P05-02Challenges and opportunities in the use of technology and AI in dementia risk reduction: the LETHE ecosystem

Sten Hanke
University of Applied Science - FH Joanneum

A cornerstone of the LETHE project is the digitally-enabled intervention that leverages Information and Communication Technology (ICT) to provide a comprehensive lifestyle intervention program and track user progress. This approach is designed to benefit all potential users by offering an easy-to-use and engaging setup. In the future, digital biomarkers—such as digital footprints from daily life—could enhance the diagnosis of chronic diseases.

Additionally, LETHE aims to use Artificial Intelligence (AI) to predict the development of risk factors, allowing for more effective and personalized interventions for individuals at risk. This session will introduce the ICT setup of LETHE, share technical insights from the two-year intervention study, and explore the potential opportunities that AI brings to the project.

P5. LETHE

P05. How technology and Artificial Intelligence can contribute to personalised risk reduction and prevention in dementia: learnings from the Lethe project

P05-03Behavior change to reduce dementia risk: an interactive and participatory process to design digital applications that support motivation and adherence

Jeroen Bruinsma[1], Jeroen Bruinsma[2]
[1]Maastricht University, [2]Maastricht University, department of Health Promotion

This session presents the iterative process of designing and deploying digital applications to promote behavior change that are integrated in the LETHE intervention. First, qualitative research was used to assess the public's openness towards dementia risk reduction and lifestyle changes. This was followed by large-scale observational research involving 4,104 Dutch adults aged 40-79, focusing on socio-cognitive determinants that drive behavior change. The findings informed the selection of behavior change methods and the design of digital applications integrated into the LETHE digital application. One feature is a system that classifies participants into lifestyle pathways (green, yellow, red) using smartphone and Fitbit data. This facilitates unobtrusive monitoring of adherence and personalized feedback to enhance motivation. New research endeavors aim to further enhance this system with Machine

Learning methods to predict behavior (change) and proactively support older adults in the process towards a healthy lifestyle.

P5. LETHE

P05. How technology and Artificial Intelligence can contribute to personalised risk reduction and prevention in dementia: learnings from the Lethe project

P05-04The two-year multinational randomized controlled LETHE trial - progress and first results

Elisabeth Stoegmann, Elisabeth Stoegmann
Medizinische Universität Wien

The LETHE trial evaluates the feasibility of a digitally supported, adapted FINGER intervention by including older adults with digital experience and increased dementia risk. 160 Participants were enrolled at four sites in Austria, Finland, Italy, and Sweden. At baseline, participants were randomized in a 1:1 ratio to 1) an intervention group comprising of a structured multimodal lifestyle program including management of diet, exercise, cognitive training, vascular/metabolic risk management, social stimulation, and sleep/stress management) or 2) to a control group with a self-guided program delivering solely regular health advice. In this session progress and first outcomes of this trial will be presented.

P5. LETHE

P05. How technology and Artificial Intelligence can contribute to personalised risk reduction and prevention in dementia: learnings from the Lethe project

P05-05Involving members of the public in designing and conducting the Lethe study

Ana Diaz
Alzheimer Europe

Public Involvement in research means research that is done 'with' or 'by' the public, not 'to', 'about' or 'for' them. It means that people affected by a disease or condition contribute to how research is designed, conducted and/or disseminated. The Lethe consortium deemed crucial to explore and include in the project the perspectives of people affected by or with an interest in Alzheimer's disease (AD) and brain health. To do so, an Advisory Board (AB) was set up at the beginning of the project which was composed of 7 people with and without cognitive problems from the 4 countries in the Lethe study. The AB has met regularly and has provided ongoing feedback and advice to the research team on several different topics. The presentation will describe some of the lessons learned on how to organise an international AB for brain health projects and the impact of this work in the project.

Innovation in care and research - Artificial intelligence

P06. Artificial intelligence

P06-01Computerized decision support to optimally funnel patients through the diagnostic pathway for dementia

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Background: The increasing prevalence of dementia and the introduction of disease-modifying therapies (DMTs) highlight the need for efficient diagnostic pathways in memory clinics. We present a data-driven approach to efficiently guide stepwise diagnostic testing for three clinical scenarios: 1) syndrome diagnosis, 2) etiological diagnosis, and 3) eligibility for DMT.
Methods: We used data from two memory clinic cohorts, including 504 subjects with dementia (302 Alzheimer's disease, 107 frontotemporal dementia, 35 vascular dementia, 60 Lewy body dementia), 191 with mild cognitive impairment, and 188 controls. Tests included digital cognitive screening (cCOG), neuropsychological assessment (NP), MRI, and CSF biomarkers. Sequential testing followed a predetermined order, guided by diagnostic certainty (Fig 1). Diagnostic certainty was determined using a computertool that generates a disease state index (DSI), indicating the probability of the (syndrome/etiological) diagnosis. Diagnosis was confirmed if the DSI exceeded a predefined threshold based on cutoffs relevant to each clinical scenario. Diagnostic accuracy and additional testing were assessed at each step. Results: cCOG as a prescreener for 1) syndrome diagnosis had the potential to accurately reduce the need for extensive NP (42%), resulting in syndrome diagnosis in all patients, with a diagnostic accuracy of 0.71, comparable to using NP alone. For 2) etiological diagnosis, stepwise testing resulted in etiological diagnosis in 80% with an accuracy of 0.77, with MRI needed in 77%, and CSF in 37%. When 3) determining DMT eligibility, stepwise testing (100% cCOG, 83% NP, 75% MRI) selected 60% of patients for confirmatory CSF testing and eventually identified 90% of the potentially eligible patients with Alzheimer dementia.
Conclusions: A data-driven tool holds promise for assisting clinicians in selecting tests of added value across different clinical contexts. This becomes especially important with DMT availability, where the need for more efficient diagnostic pathways is crucial to maintain accessibility and affordability of dementia diagnoses.

Innovation in care and research - Artificial intelligence

P06. Artificial intelligence

P06-02We all want something to care for: the LOVOT social robot as companions for older adults in canadian long-term care homes

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Loneliness and social isolation are pressing challenges experienced by older adults in long-term care (LTC) homes. Artificial Intelligence (AI) enabled social robots, such as LOVOT, are promising tools that can help facilitate connection and foster well-being. Our study aimed to investigate how the LOVOT social robot could address loneliness and facilitate connection with older adult residents of Canadian LTC homes. This study is an extended arm of a three-country study with Singapore and Hong Kong. We introduced two LOVOT robots to a Canadian LTC home for four weekly interaction sessions. Residents and family members were invited to participate in these interaction sessions. Data collection consisted of observational field notes and conversational interviews with residents (n = 37) and their family members (n = 7), focus groups with staff (n = 23), and interviews with leadership (n = 4). Thematic analysis revealed several ways in which the LOVOT robots could support the well-being of older adults: by providing companionship, which can be particularly beneficial for those with limited mobility or cognitive impairments; by fostering a sense of mattering through its responsive design; thereby reinforcing feeling of being an active and valued part of a social relationship; and by catalyzing conversations and connections with other people about what was important to them. We discuss the benefits and challenges of using AI-enabled social robots in LTC homes. We also discuss findings in the context of our international study and implications for the cultural context when introducing these innovative technologies.

Innovation in care and research - Artificial intelligence

P06. Artificial intelligence

P06-03Modeling the cognitive impact of amyloid-targeting treatments with SimulAD

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Molecular Imaging, Geneva University Hospitals and CIBM Center for Biomedical Imaging, Geneva University Hospitals

Background: Four anti-amyloid monoclonal antibodies have recently completed large phase III trials. Longitudinal amyloid PET evaluations have consistently shown the ability of all drugs to effectively reduce amyloid burden, at various rates, while cognitive outcomes were variable. In particular, donanemab and lecanemab met the targeted cognitive outcomes, aducanumab's results were controversial and gantenerumab's were negative. Their effect on slowing tauopathy was absent or sparsely documented. We explore the relationship between rate of amyloid lowering and speed and amplitude of cognitive benefits via SimulAD, a published Disease Progression Model adapted for the task.
Method: We trained SimulAD on an amyloid positive population drawn from the ADNI database, using cognitive and imaging biomarkers, including tau PET. We simulated the amyloid clearance profile of the four aforementioned drugs in five clinical trials during 18 months (N=500 for each arm, Centiloid mean 88.20 ± 5.93, Tau Fusiform SUVr mean 1.56 ± 0.08), and constant treatment effects thereafter.
Results: We found that a faster reduction of amyloid burden is accompanied by cognitive benefits within 18 months when it's coupled with a fast reduction of tau load. For example, we found that a 10% slowing of cognitive decline measured by CDR-SB is achieved within 7.8 months when amyloid and tau are slowed by at least 80% and 22%, respectively (donanemab-like trial), whereas the same cognitive benefit in a gantenerumab-like trial (slower amyloid lowering) is only achieved 33 months after the trial onset, at which point amyloid and tau are lowered by 36% and 10%.
Conclusions: SimulAD modeling of the cognitive impact of four amyloid-targeting treatment confirmed that a faster amyloid-clearing, when paired with tau-clearing, is associated with a significant cognitive benefit within the trial observed timeframe (18 months).

Innovation in care and research - Artificial intelligence

P06. Artificial intelligence

P06-04Artificial intelligence for quality of life in people with dementia: scoping review

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Background: Dementia has an impact on the quality of life (QoL) of people living with dementia. Tailored services are crucial for maintaining QoL in people living with dementia. Advancements in artificial intelligence (AI) present opportunities for people with dementia to receive personalized care, addressing specific needs as the disease progresses, potentially delaying institutionalization and enhancing overall QoL. This scoping review aims to synthesize the scientific evidence and grey literature on how AI can be used to contribute to the QoL of people living with dementia.
Methodology: Following Joanna Briggs Institute guidelines, PubMed, Scopus, and ACM Digital Library were searched in January 2024, alongside Google Scholar. Articles focusing on (i) AI, (ii) QoL, and (iii) people with dementia in various care settings were included if published in English or Dutch after 2010. Two reviewers conducted a two-stage screening process—initial title and abstract scans, followed by full-text review—to determine the articles' inclusion.
Results: After de-duplication, 4690 articles remained, which were screened based on title and abstract. This was followed by a screening process that yielded 261 full-text articles. Rigorous full-text screening resulted in the inclusion of 37 articles. AI methods were found to be used in dementia care for behavior monitoring, identifying unsafe home conditions, daily activity assistance, and companionship. Articles predominantly focused on people with mild to moderate dementia, except for companionship devices, which often focused on individuals with severe dementia. Population sizes varied widely across studies.
Conclusions: Despite the relative novelty of many AI technologies, substantial research has already been conducted. Future studies should prioritize assessing AI methods' real-life applicability and implementation to determine their long-term viability for widespread implementation in dementia care.

Innovation in care and research - Artificial intelligence

P06. Artificial intelligence

P06-05The use of intelligent technology to support clinical assessment and management of sleep disturbance for people living with dementia or mild cognitive impairment (TIMES)

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Background: Patient engagement with intelligent technology, through Chat-Bots, objective monitoring (i.e. sensors/wearables/radar), and clinical support based on complex data processing, is anticipated to improve clinical assessment and management of healthcare. However, practical, conceptual, and professional concerns, that intelligent technology may undermine the delivery of whole-person-centred primary care, remain. Chat-Bot communication can be affected by accents, speech or hearing impairment, objective monitoring may not be feasible due to privacy concerns and cognitive impairment, and there is a lack of trust in using intelligent technology to provide medical advice. We investigate the complex role of intelligent technology in a tailored intervention (TIMES) for people living with dementia (PLWD) or mild cognitive impairment (MCI) with sleep problems (https://connectedageing.org/).
Methodology: We will use semi-structured interviews to investigate whether patient and clinician engagement with intelligent-technology, including objective sleep-monitoring devices and intelligent clinical decision-making aids (patient dashboards), can support whole-person advanced generalist care for PLWD, MCI, and their carers who have sleep disturbance.
Results: We will show whether intelligent technology can support health systems to facilitate tailored care and health equity, by stratifying risk, prioritising care, and linking clinical and self-reported datasets. Preliminary findings suggest that intelligent technology could help increase time with clinicians, as patient data could be collected and collated prior to consultations. However, ethical concerns over the inability of Chat-Bots to detect emotional distress, practical issues regarding usage, and a lack of trust in intelligent technology, suggests a preference to retain empathetic elements of human interaction as part of patient care remains important.
Conclusions: Intelligent technology may support clinical decision-making processes, but patient-clinician interaction is likely to remain necessary for improving whole-person advanced generalist care.

Policy - Dementia strategies

P07. Dementia strategies

P07-01Czech National Action Plan for Alzheimer's Disease and Related Illnesses 2020 – 2030: from paper to practice

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The Czech government's adoption of the National Action Plan for Alzheimer's Disease and Related Illnesses (Plan) in 2021 marked a significant step in addressing the challenges posed by dementia. With an implementation period extending until 2030, the Plan aims to transform policy objectives into tangible outcomes in three distinct implementation phases. This study assesses the first implementation phase of the Plan, and outlines the key factors for the successful transition to the second implementation phase.

By 2023, the first phase of implementation saw the preparation of comprehensive analyses and policy documents aligning with the Plan's objectives. Notable initiatives included the development of interdisciplinary guidelines for diagnosis and post-diagnostic support, and adaptation of guidelines and tools developed by the World Health Organization to the Czech context, namely the iSupport tool and the guidelines for dementia risk reduction. Additionally, criteria for dementia-friendly communities were established based on a regional pilot study, serving as a foundation for future initiatives.

As the Plan progresses into its second implementation phase, the focus shifts towards piloting, evaluating, and integrating new services and activities into practice. However, significant challenges persist, primarily due to the fragmented nature of funding, which has impeded progress in the initial phase and poses a threat to future implementation efforts. Synergies between the Plan and other health policy initiatives, such reforms of mental health or geriatric care, and engagement into international collaboration, such as projects funded under the EU4Health programme, offer opportunities to overcome funding constraints. Key facilitators of the implementation process include the established role of the national dementia coordinator and the oversight provided by the ministerial advisory stakeholder platform.

Policy - Dementia strategies

P07. Dementia strategies

P07-02Advancing dementia care: implementation of the Austrian Dementia Strategy "Living well with Dementia" – new developments

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The implementation of the Austrian Dementia Strategy (2015) commenced in 2016, calling upon all stakeholders to actively engage in their respective domains to bolster the Strategy's efficacy. Their collective efforts aim to foster a deeper comprehension of dementia and eradicate associated stigmas.
The Ministry of Social Affairs, Health, Care and Consumer Protection (BMSGPK) has initiated various measures to aid individuals with dementia and their caregivers. These include provisions such as hardship supplements for long-term care allowances and counselling sessions, including home visits. Presently, the Austrian Dementia Quality Register (DQR) - implemented by the Austrian National Public Health Institute on behalf of the BMSGPK - is in its final stages thereafter a pilot program is to be rolled out. The Austrian Alzheimer Society has been steadfast in its support of the project since its inception.
The main objective of the Austrian DQR is to gather socio-health data concerning individuals with dementia and their caregivers, utilizing scientifically defined metrics. This data will serve as a foundation for enhancing the landscape of care, with the overarching goal of improving both the quality of care and the quality of life for those affected by dementia and their families. Furthermore, the project endeavours to furnish vital insights into contemporary dementia care practices while plotting the route of care and nursing developments.
The presentation will highlight current measurements and ongoing efforts aimed at supporting people with dementia as well as their caregivers and share first impressions and results on the initial pilot of the DQR (summer 2024).

Policy - Dementia strategies

P07. Dementia strategies

P07-03An overview of the model of care for dementia in Ireland and its implementation

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The Model of Care (MoC) for Dementia in Ireland sets out the optimum care and support pathways for people living with dementia, from the point of concern when first noticing symptoms (e.g. change in cognition, behaviour, memory, mental health, mood or personality) to receiving a variety of supports in the community and at home. It describes adaptable pathways of care that maximise the use of existing structures, the enhancement of current services and new service requirements. It also outlines integrated working across services and personalised care to reach the outcomes most important for each individual.

Specifically, the model includes guidance on:

- Dementia assessment and targets for diagnostic services.
- An outline of the dementia diagnostic pathway and the required assessment service infrastructure, describing three levels within the assessment and diagnostic pathway.
- Guidance on best practice and key steps in communicating a diagnosis of dementia.
- Recommendations on the key elements of personalised care planning.
- Targets and recommendations on early post-diagnostic support and details on the dementia post-diagnostic care pathway with examples of supports and interventions, which can be provided across five strands of support.

The MoC seeks to place Ireland to the fore internationally in our approach to brain health, cognitive impairment and dementia, and ensure the delivery of timely and effective assessment and the enhancement of integrated dementia services in Ireland.

The MoC places the person with dementia at the centre of care planning and decision-making, promoting an outcome focused approach that meets each of the aims of the Health Service Executive Corporate Plan

Implementation of the MoC has begun with a number of services becoming operational and will assist Ireland in meeting the targets set out by the World Health Organisation's Global Action Plan on Dementia (2017-2025), across the seven action areas.

Policy - Dementia strategies

P07. Dementia strategies

P07-04What does the Spanish population think of and know about Alzheimer's? Results from a public opinion survey

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[1], [2]Pasqual Maragall Foundation

To promote public debate and social awareness on Alzheimer's along with the promotion of scientific research to find effective solutions is of the utmost importance. Gathering the opinion of the general population represents an excellent basis from where to boost ideas to address relevant gaps. In this context, the Pasqual Maragall Foundation conducted a public survey with three objectives: 1) providing a comprehensive analysis of perceptions, knowledge, and attitudes in relation to Alzheimer's, and its research; 2) identifying areas of disinformation to propose actions aimed at improving the level of general knowledge; 3) providing these data to associations and other institutions involved in addressing it.
This work includes 2,395 responded questionnaires in a representative Spanish sample considering the regional distribution of the country. Topics addressed include (among others): level of knowledge, proximity and concern about Alzheimer's, attitudes toward risk determination or early diagnosis, and opinions on research and willingness to participate in scientific studies.
Some of the highlighted results are: the Spanish population has information about the basic aspects of Alzheimer's although with gaps on relevant issues; Alzheimer's is the second health condition that mainly concerns the Spaniards and is regarded the main health condition aged persons face; two out of three Spaniards know someone diagnosed with Alzheimer's; seven out of ten believe that people feel uncomfortable talking about Alzheimer's; there's a wide predisposition to know the personal risk to be diagnosed with Alzheimer's; more than half of the population would undergo a test to know if they are in an early phase of Alzheimer's; research in treatments and early detection should be particularly prioritized. The Spanish population is highly confident that a cure will be found, despite considering that the necessary resources are not yet allocated.

Policy - Dementia strategies

P07. Dementia strategies

P07-05The public health response to dementia in Italy: lessons to promote a European strategy

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Background: As endorsed by the World Health Organization (WHO), concrete public health actions should be adopted to reduce the burden of dementia. The Italian strategy for dementia started in 2014 by developing the first National Dementia Plan, which was later financially supported by a grant of 15 million euros for three years (2021-2023). The activities presented outline the efforts and achievements of the Italian National Institutions, supported by regions and autonomous provinces, to promote a national public health response to dementia. (Project carried out with the technical and financial support of the Ministry of Health - Chapter 2302)
Results: A scenario analysis revealed that 39.5% of dementia cases can be attributed to 11 risk factors, and by reducing them by 20%, up to 67,000 can be prevented. While cardiovascular risk factors are generally addressed, an analysis of health policies showed that no dementia-specific strategies exist for hearing loss, education, and depression. A National Guideline was developed, consisting of 167 clinical and 39 research recommendations. An economic evaluation showed expenses of €23.5 billion. A national survey showed a median diagnostic delay of 12 months and average out-of-pocket costs of €1,800/month. Focus groups with carers identified unmet needs in health services and campaigns on inclusivity. A census of Dementia Friendly Communities identified 57, spread across North (77%), Centre (9%), and South (14%). Information on all Italian memory clinics, daycare centres, and nursing homes was collected and uploaded to a dedicated website.
Conclusions: Adopting the WHO Global Action Plan on Dementia as a common language to facilitate international communication, we described the Italian scenario aiming to promote a European strategy for the public health response to dementia, focusing on the harmonisation of best practices, coordination of research and innovation activities, and advocacy for dedicated science-for-policy initiatives.

P08. Alzheimer Switzerland - Vulnerable Groups

P08. Vulnerable Groups: The Swiss situation

P08-01Improving dementia care for people with a migration background: addressing cultural barriers and developing migration-sensitive support services

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Background: The care of People with Dementia (PwD), in particular those with a Migration Background (MB), is a major public health challenge in Europe. Many countries have recognised their problems and support needs and have outlined them in their national dementia strategies.

Results: PwD and MB as well as their caregivers have different interpretations of dementia. How they deal with the disease and their attitude are strongly influenced by their cultural background. They describe their experience with healthcare professionals regarding the use of support services as unsatisfactory. Healthcare professionals report obstacles and difficulties in meeting the needs and expectations of those affected and their caring relatives.

Discussion: Designing migration-sensitive care for PwD and MB primarily requires an understanding of their living environment and their caregivers, their perceptions and experiences regarding the disease, care and support, and their attitudes regarding the use of external support.

Implications for practice and research: To effectively design migration-sensitive outpatient care for PwD and with a MB, several key strategies are recommended. First, it is essential to raise awareness and provide comprehensive education about dementia among both healthcare providers and the general public. Additionally, there should be a focus on increasing the understanding of the life situations and specific needs of these individuals. Developing migration- and culture-sensitive competencies among healthcare professionals is crucial, as is the inclusion of multilingual staff in dementia care. Finally, fostering the intercultural openness of care facilities will help create a more inclusive and supportive environment for all individuals.

P08. Alzheimer Switzerland - Vulnerable Groups

P08. Vulnerable Groups: The Swiss situation

P08-02People with intellectual development disorders who develop Alzheimer's dementia - a particular challenge for care institutions in Switzerland

Dan Georgescu
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In Switzerland, there are separate care systems for people with intellectual developmental disorder and people with Alzheimer's dementia. These differ both in terms of how they are embedded in the care system and how they are financed. The care concepts and the professions of the specialist staff in the two types of care institutions also differ significantly. When people with intellectual development disorders, e.g. Down's syndrome, develop Alzheimer's dementia, the skills and services offered by facilities for people with intellectual disability are no longer sufficient to ensure optimal care. However, there is also an immense challenge for nursing home staff specializing in dementia to take over, as nursing home staff largely lack the specific developmental psychology and socio-pedagogical knowledge and skills. Ways out of this "care dilemma" are presented and discussed.

P08. Alzheimer Switzerland - Vulnerable Groups

P08. Vulnerable Groups: The Swiss situation

P08-03Implementing high-quality care for persons with dementia in acute hospitals: recommendations for practice development

Laura Adlbrecht, Heidi Zeller, Nicole Helfenberger
OST - Eastern Switzerland University of Applied Sciences

Background & aim: Adequate care for people with dementia in hospitals is often hindered by strong traditions, rigid structures and insufficient staff numbers and skills. Our aim was to develop recommendations for sustainable practice development to implement appropriate care for people with dementia.

Methods: In a two-part qualitative study, we conducted individual interviews and focus groups with 14 participants who shared their experiences of implementing dementia care in hospitals. In addition, Lego Serious Play workshops were conducted with 22 healthcare

professionals and lay people to gather more information about overcoming barriers. The data were analysed using structured content analysis and knowledge mapping.

Results: We have identified four core activities that are crucial for the successful development of structures, processes, competences and attitudes of employees: (1) Role modelling: A clear vision, represented by a transformational leader and a multi-professional core group, is essential. (2) Persuading: Convincing managers at all levels, staff and stakeholders outside the hospital requires consistent lobbying and making dementia care more attractive, e.g. through incentive systems. (3) Empowering requires modelling person-centred values and developing skills through formal and informal learning opportunities. The use of champions in everyday clinical practice is important. (4) Enabling: Processes must allow for variation, creativity and experimentation. Case leaders should be appointed to coordinate information, people and processes. It also requires more skilled staff and an optimised environment. The four core activities influence each other and should be iterative.

Discussion & conclusion: Developing high-quality care for people with dementia in hospitals requires the broad involvement of people from different professions and management levels. It is not only necessary to inform and educate on the basis of a mission and a project plan, but also to convince and empower. A long-term perspective and consistency seem to be central.

P08. Alzheimer Switzerland - Vulnerable Groups

P08. Vulnerable Groups: The Swiss situation

P08-04Family caregivers at risk: the cost of dementia in Switzerland

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Dementia not only affects the person with the disease but also has a profound impact on their family. Relatives often take on the demanding task of caring for a person with dementia for many years, which can be an enormous burden and lead to a deterioration in their physical and mental health. In addition to these health implications, dementia also has financial consequences.

In order to raise awareness of the monetary costs of dementia and the potential burden on family caregivers, it is essential to have figures about the cost of dementia. Therefore, the aim of our study conducted in 2019 was first to calculate the total societal costs of dementia, including the costs of informal care provided by family members, and second, to estimate the individual costs of appropriate care for people with dementia in Switzerland, depending on the stage of dementia and the housing situation.

The results of the study show that the annual cost of dementia amounts to CHF 11.8 billion, of which informal care accounts for almost 50%. These indirect costs include the unpaid hours that family caregivers invest on a daily basis. The results also show that the cost of adequate dementia care would be relatively high, particularly with advanced disease progression, and that there are large regional differences.

Therefore, we conclude that dementia is a time and financial burden that increases the risk of poverty in old age while also increasing the risk of reduced well-being for family caregivers. It is therefore crucial to provide affordable support and respite services for people with dementia and their relatives.

P08. Alzheimer Switzerland - Vulnerable Groups

P08. Vulnerable Groups: The Swiss situation

P08-05Sex and gender differences in Alzheimer's patient journey and caregiving

Mariapaola Barbato
Women's Brain Foundation

Alzheimer's disease (AD) is a severe and progressive neurological condition that significantly impacts the lives of patients and their caregivers. Research on the impact of sex and gender on AD has been rapidly growing in recent years. There is now extensive evidence showing that sex differences affect risk factors, symptomatology, treatment efficacy and disease trajectory of AD. Women represent two thirds of all patients, and their lifetime risk of developing AD is higher than men's. This talk will focus on sex and gender differences along the AD patient journey, including awareness of risk factors, mode of AD diagnosis, therapies and treatment adherence. The role of caregiver and how it differs between men and women, will also be discussed. An improved understanding of the patient's journey from a

female/male perspective is crucial to improve diagnosis and outcomes for those affected by AD.

Patient pathways - Detection and diagnosis

P09. Detection and diagnosis

P09-01Facilitators and barriers of using digital tools to assess cognition: a focus group study among people at risk for or living with Alzheimer's disease

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Background: Cognitive testing is an important part of the diagnostic work-up for Alzheimer's Disease (AD). However, traditional pencil-and-paper tests are often perceived as burdensome. Digital tools might offer a solution because they are less burdensome, costly, and time-consuming. Digital tools to assess cognition are increasingly available, yet do not often find their way into daily practice. To foster implementation, better insight in what potential end users identify as facilitators and barriers of digital testing is needed.
Methods: Five focus groups were organized with healthy elderly (n=14), older adults with subjective cognitive decline (n=11) and mild cognitive impairment (n=4) with biomarker-confirmed AD, and their caregivers (n=2). In two hours, barriers and facilitators were identified and discussed in the group. To facilitate the discussion, three examples of digital tools were introduced across the continuum from active to passive assessment. Audio transcripts were manually transcribed and analyzed using thematic analysis by two independent coders.
Results: We identified three main themes, that followed the patient journey as depicted in Figure 1: 1) test motivation, 2) digital tools as the right measure for cognitive testing and 3) digital test characteristics. Subthemes indicated personal preferences that differed and contradicted among individuals. For example, test motivation was facilitated by the prospect of early disease recognition, while impeded by the fear of a dementia diagnosis. Concerning digital tools as the right measure, lack of personal contact could be both a facilitator and a

barrier, “I think I'd feel quite alone with just my iPad”. User-friendliness was identified as an important test characteristic, “people should enjoy using it”, indicating that the test should be attractive, but not too childish.
Conclusion: To stimulate implementation in daily practice, we advise to use digital tools with a personalized approach, while addressing facilitators and barriers according to the place in the patient journey.

Patient pathways - Detection and diagnosis

P09. Detection and diagnosis

P09-03Perspectives of general practitioners on implementing blood-based biomarkers for Alzheimer’s disease in primary care

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Background: Adequately diagnosing Alzheimer’s disease (AD) in primary care can be challenging as general practitioners (GPs) are currently not equipped to diagnose AD biologically. AD blood-based biomarkers could improve the diagnostic process for persons with cognitive complaints in primary care. We aim to investigate implementation barriers and facilitators from the perspective of GPs.
Method: In this qualitative, semi-structured interview study, we used purposive sampling to recruit a heterogeneous group of 18 Dutch GPs. To identify and categorize implementation barriers and facilitators, audio-recorded and transcribed interviews were analyzed using MaxQDA software by means of directed content analysis using the Theoretical Domains Framework (TDF). Result: We identified 8 relevant TDF domains. Key barriers could be mapped on the environmental context and resources (e.g. GPs need additional time to explain AD blood test to patients), knowledge (e.g. GPs perceived AD-dementia as a

syndromic diagnosis, not a biological diagnosis), emotions (e.g. GPs feel uncomfortable regarding an early AD diagnosis), skills (e.g. GPs do not know how to explain AD blood test to patients) and beliefs about consequences (e.g. AD blood-based biomarkers could result in over- or underdiagnosis of AD) domains. Facilitators could be mapped onto the environmental context and resources (e.g. availability of education and accessible information for GPs and patients), social influences (e.g. GPs believed persons with cognitive complaints and his/her supporters choose whether to be tested for AD), beliefs about consequences, and memory, attention and decision processes (e.g. GPs believed that AD blood-based biomarkers could initiate care, facilitate decision-making and provide clarity regarding the diagnosis) domains.
Conclusion: We identified an extensive variety of implementation barriers and facilitators. We suggest that more education and information about AD blood-based biomarkers is needed to facilitate implementation. Our next step is to further explore implementation determinants by means of focus groups and a large scale questionnaire.

Patient pathways - Detection and diagnosis

P09. Detection and diagnosis

P09-04Associations between glucose metabolism measures and amyloid and tau load on PET 14 years later: findings from the framingham heart study

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Objective. Type 2 diabetes and glucose metabolism have previously been linked to Alzheimer's disease (AD). Yet, associations of glucose metabolism with amyloid and tau pathology later in life remain unclear. This knowledge will help understanding the importance of glucose regulation in relation to AD. Research Design and Methods. We included 288 participants (mean age = 43.1, SD = 10.7, range 20-70) without dementia from the Framingham Heart Study (FHS), who had available glucose metabolism measures (i.e.,

fasting plasma glucose and insulin) and PET measures of amyloid and/or tau 14 years later. We performed linear regression analyses to test associations between plasma glucose (continuously and categorically; elevated defined as >100 mg/dl), plasma insulin, insulin resistance and amyloid or tau load on PET. We also explored whether age, sex, APOE ε4 allele carriership modified these associations, and whether amyloid load modified the associations between glucose metabolism and tau. Results. Our findings indicate that elevated plasma glucose was associated with greater tau load in the brain 14 years later (B[95%CI] = 0.03 [0.01 – 0.05], p = 0.006, p = 0.024 after false discovery rate (FDR) correction), independent from amyloid load. APOE ε4 carriership modified this association (B[95%CI]: -0.08 [-0.12 – -0.03], p = 0.001), showing that the association was only present in APOE ε4 non-carriers (n = 225). Increased plasma insulin and insulin resistance were associated with decreased amyloid load after 14 years (B[95%CI] = -0.01 [-0.02 – -0.00], p = 0.035 and B[95%CI] = -0.01 [-0.02 – -0.00], p = 0.034, respectively), but this association was attenuated after FDR correction (both p = 0.07). No other associations were found. Conclusions. Our findings suggest that regulation of plasma glucose is important to prevent future tau pathology later in life. This provides relevant knowledge for prevention strategies and prognostics to improve healthcare.

Patient pathways - Detection and diagnosis

P09. Detection and diagnosis

P09-05Exploring APOE genotypes and plasma p-tau biomarkers in European MCI populations: insights from the AI-MIND project

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Dementia represents an escalating global challenge, with nearly 10 million new cases yearly, largely driven by Alzheimer's disease. Mild cognitive impairment (MCI) is a crucial transitional stage between typical brain aging and dementia, affecting over 10 million Europeans. This condition holds significant clinical and scientific interest due to its 20-fold increased risk of dementia compared to the healthy population. The AI-Mind project is a pioneering initiative offering an innovative approach to early-risk assessment through the implementation of advanced artificial-intelligence, with the primary aim to devise an

automated tool for predicting the transition from MCI to dementia through cost-effective, widely available, accurate, and non-invasive measures. Operating across five clinical sites in four European nations (Norway+Finland in Northern Europe, Italy+Spain in Southern Europe), the project enrolled over 1000 MCI subjects from 2022 to 2024. Initial assessments involved blood sample analysis for plasma phosphorylated tau biomarkers (p-tau181 and p-tau217) and genetic profiling for APOE genotype determination. As of May 2024, APOE ε4 carriers constituted 32.17% of the analysed subjects (including 15.3% homozygotes), with 67.83% being non-carriers. Regional variances in APOE ε4 prevalence were noted, with higher rates observed in Northern Europe (41.3%vs.23.59%), while the prevalence of APOE ε2 carriers were similar. Both plasma p-tau biomarkers exhibited significant associations with APOE genotype and geographical location, with higher levels in APOE ε4 carriers and Southern European populations in binomial regression models controlled for age and sex. While regional differences in the prevalence of APOE genotypes are well-documented, the associations between novel plasma p-tau biomarkers and APOE genotype, particularly within MCI subjects, remain relatively unexplored. Moreover, to our knowledge this study presents the first evidence of geographic variations in these biomarkers across Europe. These findings underscore the necessity for further investigations, particularly in delineating potential implications for future diagnostic and prognostic algorithms utilizing these novel biomarkers.

Living with dementia - Housing and neighbourhoods

P10. Housing and neighbourhoods

P10-01How do we build dementia-friendly environments and houses?

Anne de Boer
Alzheimer Nederland

The Netherlands is dealing with a rapidly aging population. Since aging is a risk factor for dementia, there will be more people with dementia living in the Netherlands. Simultaneously, the number of healthcare professionals and caregivers will not increase. Living independently in your own home, also known as aging-in-place, is the preferred way of growing older. The policy of the Netherlands has set an ambitious goal to build 300.000 houses for older people between now and 2030. Alzheimer Nederland wants these houses to be dementia-friendly, because there will be a high chance that some of the residents have dementia. Only in dementia-friendly housing we can uphold the quality of life and safety of people with dementia and their caregivers.

Because the environment significantly impacts people with dementia, we need to think about how we design homes and neighborhoods to help them be more independently. To help them live comfortably and safely, we can design homes in a way that suits their needs. Alzheimer Netherlands, Woonzorg Netherlands, and Eindhoven University of Technology worked together to create a toolkit for building dementia-friendly houses. This toolkit is for builders, architects, residents, and healthcare organizations. It covers different stages of building, like planning, construction, and maintenance. It's not just for new buildings but also for changing existing ones to be more dementia-friendly.
The toolkit uses pictures and simple explanations to show how to make homes better for people with dementia. It includes practical exercises and real-life examples to help people understand and talk about dementia-friendly building.

Living with dementia - Housing and neighbourhoods

P10. Housing and neighbourhoods

P10-02Alzheimer's homesharing, an other solution?

Christine Tabuenca[1], Marie Gannac[1], Alain Berard[2], Jérémy Kozick Rigaud[2]
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Introduction: When cognitive disorders become severe for people to remain at home, the only solution is often to move them to a nursing home. Moving into a nursing home is often neither a right nor a choice and remains complex. An IFOP survey carried out in 2021 for the Fondation Médéric Alzheimer shows that very little is known about inclusive and alternative housing: 28% of French people have heard of it and 6% know exactly what it is. Alzheimer's homesharing is one of the new ways of living. In order to understand how this new solution is transforming the way we support people with Alzheimer's disease, the Fondation Médéric Alzheimer conducted a mixed-method study.
Method: Two studies:

- An observational study of 6 Alzheimer's homesharing. A monograph presenting their specificities was produced for each and enabled us to identify the strengths and weaknesses.
- A quantitative survey to support the initial findings and gain a better understanding of the business model.

For example, the number of the people living on and the presence of 24/24 human assistance mean that the life is more confortable, with fewer crises and less aggression. Families are at the heart of the system. They participate in daily life. However, the study also highlights a precarious economic model, high out-of-pocket expenses, and a lack of training and supervision for caregivers…
Results: 67 Alzheimer's homesharing were contacted in 2023 with 98% return rate.
Conclusion: A better understanding of the full range of solutions is needed to better anticipate the progression of the disease, respect the person's choice of lifestyle and enable them to exercise their free will, "right to the end".

Living with dementia - Housing and neighbourhoods

P10. Housing and neighbourhoods

P10-03The changing seasons: conducting participatory ethnographic work with people living with dementia in their garden at home

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[1]The University of Manchester, [2]ImaginationLancaster, Lancaster Institute for Contemporary Arts, Lancaster University., [3]Division of Nursing, Midwifery and Social Work, School of Health Sciences, the University of Manchester / Greater Manchester Mental Health NHS Foundation Trust.

Spending time in the garden enables people living with dementia to maintain a sense of continuity and identity by connecting to nature, people, and to the moment, whilst managing everyday life. However, in sharp contrast to ‘away from home’ outdoor activities, including horticultural therapy, relatively little is known about the domestic garden and the everyday experience of living with dementia, including the significant value people gain from simply being in a garden/outdoor space at home and its capacity to improve quality of life (Newton et al., 2021).

To address this gap in knowledge and drawing upon a participatory ethnographic approach, seven households living with dementia within the Northwest of England shared their experiences with the research team of accessing and using their garden at home. These everyday interactions were recorded using participant observation and impromptu conversations coupled with photographs. Contact with each household took place over a

period of six weeks and were staged so that all seasons of the year were included. Data were analysed using thematic analysis.

In the presentation, stories and pictures from the garden will be shared that reflect the changing nature of the seasons and the use of the garden by people with dementia, including the threshold spaces (such as sheds and summerhouses) that hold meaning and value. Importance will also be given to the sensory nature of being outdoors and how the garden created a place of contentment and growth and living positively with dementia.

Reference: Newton, R., Keady, J., Tsekleves, E., and Adams, S. 'My father is a gardener…': a systematic narrative review on access and use of the garden by people living with dementia. Health and Place, (2021) 68:102516.

Living with dementia - Housing and neighbourhoods

P10. Housing and neighbourhoods

P10-04What experiences do people living with dementia and their carers have with the neighbourhood-built environment and what effects do they have on social health?

Janissa Altona[1], Emily Mena[2], Benjamin Schuez[2], Karin Wolf-Ostermann[2]
[1]University of Bremen, [2]

Several studies point to the importance of the neighbourhood-built environment (NBE) for the social health of people with dementia (PlwD) in the living environment. Although there are clear indicators for dementia-friendly urban planning that can be identified from literature, they are not currently evaluated according to their relevance on a participatory basis. Since certain aspects of the NBE are particularly important for social health (e.g. green and walking areas, orientation infrastructure or meeting places) they should be assessed by those affected in terms of their everyday relevance. In order to demonstrate the subjective impact of the NBE, the DEN-HB project will conduct a qualitative study based on a quantitative questionnaire previously developed in the course of the project and currently used to assess dementia-friendly neighbourhoods based on 3,000 randomly selected geo-coordinates within neighbourhoods in the city of Bremen, Germany.
Initially, eight guideline-based semi-structured individual interviews will be carried out with PlwD of the European Working Group of People with Dementia and carers of the European Dementia Carers Working Group to discuss the relevance of single indicators of dementia-

friendliness of the NBE. In addition, a focus group (n=8) will be conducted with dementia coordination centres and responsible persons from ministerial institutions in Bremen to discuss highly rated indicators and possibilities for action in urban planning in Bremen. The results show that indicators are rated differently by PlwD which underlines the importance of a differentiated view on indicators assessing NBE factors. Based on these results, further research will be conducted to develop the quantitative questionnaire into a weighted standardised questionnaire on the dementia-friendliness of the NBE for PlwD.

Living with dementia - Housing and neighbourhoods

P10. Housing and neighbourhoods

P10-05Odense houses: a place and a voice for people with dementia

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As aging-in-place, or living independently in one's own home is the preferred way of growing older, Dutch policy has set the ambitious goal to establish drop-in centres for 80% of people with dementia in all neighborhoods by 2030.

Odense houses form the largest group of drop-in centres in the Netherlands. The sixty Odense houses are civilian initiatives that prioritize inclusivity, mutual support and a sense of community as core as core values, drawing inspiration from a Danish concept. A distinctive characteristic of Odense houses is that a diagnosis is not required. This makes Odense houses a place where people with early signs of dementia and their support network can connect with people facing similar situations. Participants organize activities such as hiking, yoga, lectures, music, painting or any other activity they enjoy. Participants can join activities at their convenience and come and go as they please.

Odense houses play an important role in addressing societal challenges such as loneliness among older adults as well as the rising costs and shortages of formal care staff. These drop-in centres operate with fewer personnel and postpone the need for formal care.

We are excited to present the Odense house concept at this year's conference, together with one of our participants living with dementia, as this aligns with our philosophy of inclusion.

The National Platform of Odense houses, the umbrella organization connecting all Dutch Odense houses, participated in the Erasmus+ project 'Embrace dementia in an online environment'.

Our knowledge and innovative social apporoach of contributes to the improvement of dementia education and raising awareness throughout the Netherlands. The National Platform of Odense houses has established a formal partnership with Alzheimer Nederland.

P11. Emeis

P11. What evidence in 2024 to better care people with Alzheimer's disease in nursing homes?

P11What evidence in 2024 to better care people with Alzheimer's disease in nursing homes?

Pierre Krolak-Salmon[1], Kevin Charras[2], Joel Belmin[3], Sandrine Andrieu[4], Avidan Kogel[1]
[1]emeis, [2]CHU de Rennes, [3]AP-HP, [4]Institut Hospitalo-Universitaire HealthAge

During this session, we will review the current best evidence on the care of people living with dementia in nursing homes. New scientific data allow now to build a comprehensive care and therapeutic approach combining different engines to support both health and quality of life of demented residents.

Dr Kevin Charras, psychologist, will review the non-pharmacological or psychosocial interventions we have to prioritize for our residents, since the level of evidence is quite heterogeneous in the field.

Complementary to these approaches, new studies disclose the long-term benefits of symptomatic drugs (choline esterase inhibitors and memantine), that will be explained by Pr Joel Belmin, geriatrician. Cardiovascular, cerebrovascular and mortality will be particularly considered.

Other secondary prevention programs like physical activities, diet balance, social interaction and a panel of other important factors have to be proposed. The evidence in literature will be summarized by Pr Sandrine Andrieu, epidemiologist, specialist of Alzheimer's disease.

Lastly, nice innovative initiatives regarding smart environment and real estate fitting with residents' wills and needs will be proposed by Dr Avidan Kogel, geriatrician from the Group *emeis*.

All these vectors of secondary and tertiary prevention of severe stages and complications of dementia are now associated to good scientific evidence. It is our duty to hierarchize and prioritize the best ones to help people keeping the best quality of life.

Inclusion and intersectionality - Minority ethnic groups

P12. Minority ethnic groups

P12-01Raising awareness about dementia in Austrian, German, Greek and Italian Deaf communities: the De-Sign Erasmus+ project

Marianna Tsatali[1], Athanasia - Lida Dimou[2], Enrico Dolza[2], Doris Hoffmann-Lamplmair[2], Tarsitsa Ntova[2], Ioanna Antigoni Angelidou[2], Marie-Luise Burgstaller[2], Kiriaki Chatziavannidou[2], Theodoros Goulas[2], Nicola Della Maggiora[2], Romeo Seifert[2], Thomas Ströbele[2], Magda Tsolaki[2], Birgit Teichmann[2]
[1]Greek Association of Alzheimer's Disease & Related Disorders, [2]

Background: According to studies, Deaf people have quite limited access to dementia-related information, because dementia raising campaign do not include information in sign language (SL), which limits the access to this population. Hence, dementia knowledge is very low across Deaf communities around the world. Method: To fill this gap, the current Erasmus+ project aims to create dementia raising awareness seminars, tailored in cultural background and norms of the Deaf communities in Austria, Germany, Greece, and Italy. Result: For the project's purposes, a group of experts adapted three well known psychometric scales measuring dementia knowledge, attitudes about dementia and confidence about dementia in German and Greek SLs. Additionally, focus groups have been conducted to learn more about Deaf people's perspective towards dementia, as well as their

information sources in order to identify any stereotypes and misunderstandings regarding dementia. After the analysis of the qualitative and quantitative results, structured seminars to promote dementia awareness will be implemented in Deaf communities of the participated countries. These seminars will include visual cues, such as diagrams, pictures and graphs which are preferable means to convey the dementia related information, rather than written texts coming from oral languages. To further disseminate the project's results, project's webpage will be presented in SL to dementia experts as well as Deaf communities. Conclusions: The goal is to implement dementia raising awareness seminars in Deaf people from Austria, Germany, Greece and Italy, in order to increase awareness and provide necessary information and subsequently upskill them in the field of dementia, break any stereotypes existing, and provide them with care pathways.

Inclusion and intersectionality - Minority ethnic groups

P12. Minority ethnic groups

P12-02Culture sensitive care and dementia diagnostics in practice: insights from the multicultural memory clinic

Najoua Lazaar[1], Janne Papma[2], Rozemarijn Van Bruchem-Visser[2], Francesco Mattace Raso[2], Sanne Franzen[2]
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The ageing population in the Netherlands is becoming increasingly diverse due to the labor migration in the 1960's and 1970's. Given the significant presence of dementia risk factors within this group, it's probable that they will require dementia diagnostics, –care and –services. Memory clinics aren't sufficiently tailored to this. In 2015 the multicultural memory clinic was established as part of the Alzheimer Center in the Erasmus Medical Center in Rotterdam, the Netherlands. Within the multicultural memory clinic there is attention for dementia diagnostics that is adjusted to the culture, language and/or level of (health)literacy of the patient. A culture sensitive approach that helps create optimal conditions for diagnostics.
In the multicultural memory clinic different barriers are being tackled. A significant part of the ageing population in Rotterdam consists of labor migrants of Moroccan and Turkish descent. To cater to this linguistic diversity, (medical) students with a bicultural background who are proficient in these languages are encouraged to apply for a (paid) position as a

student translator. These student translators are trained to help with conducting neuropsychological assessment in the patient's language. For languages other than Moroccan and Turkish an external professional interpreter is hired. Furthermore, the TULIPA test battery is used when conducting neuropsychological assessment. The tests that are included within TULIPA take the culture, language proficiency and literacy of a patient into account. Patients that visit the multicultural memory clinic also get informed about different research that is being done within the Alzheimer Center in their own language. This helps with working towards scientific research that is more culturally diverse.
To conclude, it is important to pay attention to the increasing diversity in the ageing society. Memory clinics should be better tailored to this, so that dementia diagnostics can be applied accurately.

Inclusion and intersectionality - Minority ethnic groups

P12. Minority ethnic groups

P12-03Empowering CALD Communities: culturally tailored specialist dementia care through inclusion and intersectionality for minority ethnic groups

Sunny Traverse
Bene

This submission addresses the multifaceted challenges facing culturally and linguistically diverse (CALD) residential aged care facilities in accessing dementia care services. Integrating cultural competency, our approach aims to enhance the quality of life, well-being, and dignity of CALD older persons living with dementia, whilst providing crucial support to families and caregivers.
Emphasizing inclusion, cultural respect with access to culturally relevant support services aligned with the beliefs, practices, and cultures within CALD communities we believe is pivotal for advancing an equitable and person-centered approach to dementia care.
The Australian aged care landscape presents with barriers for provision of dementia care for CALD older persons. The Australian Department of Health and Aged Care is reviewing "The Aged Care Act" with new strengthened Quality Standards focusing on CALD communities and older persons living with dementia yet to be released.
Language barriers hinder effective interactions between CALD older persons, resulting in

misunderstandings and deficits in quality of care. Cultural subtleties further complicate communication, necessitating tailored engagement and comprehension approaches.
Resource constraints impede the implementation of culturally sensitive programs and the procurement of translation services, hindering person-centered care delivery.
Respecting end-of-life preferences, necessitates enhanced training and coordination among interdisciplinary teams. Maneuvering these preferences within the complexities of dementia care presents significant challenges.
Promoting diversity within aged care staff and fostering of cultural understanding and communication, whilst collaborating among aged care providers, government agencies, and community organisations will be vital for crafting culturally inclusive care models.
By cultivating partnerships and leveraging community resources, aged care facilities can bolster their capacity to provide person-centered care that embraces the diverse needs of older persons living with dementia, irrespective of cultural or linguistic background

Inclusion and intersectionality - Minority ethnic groups

P12. Minority ethnic groups

P12-04Good dementia care in a culturally diverse society: Insights from a qualitative study conducted with Turkish and German professionals in Germany

Ela Nadine Yüzgülen, Zümrüt Alpinar Segawa

Background: The understanding of good care is culturally shaped. Germany has the highest rate of immigration in Europe making it a culturally diverse society. There is a growing emphasis on dementia diagnosis and care for people from different cultural backgrounds. However, there is lack of services addressing the needs of people with migration background. Individuals who have a Turkish migration background constitutes the largest migrant group in Germany. The first-generation Turkish migrants represents a large potential group for dementia-related healthcare services.

Objectives: To explore empirically (a) the practical challenges experienced by professionals when providing care and counseling for people with migration background regarding dementia-related healthcare services and (b) their conceptions on good dementia care.

Methods: Nine in-depth interviews with professionals with different expertise in dementia and aging are conducted. The professionals either had a Turkish migrant background or were Germans. Thematic content analysis was conducted to extract key themes.

Results: Our first analysis showed that there are structural gaps to provide appropriate dementia care for the persons with Turkish migration background. Barriers to communicate and diagnose were identified. The needs to improve care and quality of life of the person with dementia and their families showed similarities, however needs differed when care was provided for people with Turkish migration background. Knowledge of culture, customs, mother tongue and biography were identified as key sources to provide appropriate care. Participants emphasized the need for more resources (e.g., time, staff, etc.), openness to cultural differences and more support for migrant groups.

Conclusion: Noticing cultural particularities (e.g., perceptions, cultural image, management of dementia, etc.) would promote autonomy, beneficence and justice by allowing communication and realization of options, improving the quality of dementia care and increasing persons trust in medical services. This would allow a fairer healthcare system in Germany.

Inclusion and intersectionality - Minority ethnic groups

P12. Minority ethnic groups

P12-05Understanding the support needs of African and African-Caribbean people living with dementia: an ethnographic study in the UK

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The UK population of ethnic minority people living with dementia is likely to increase sevenfold by 2050. For decades attempts to understand experiences of minority ethnic communities have typically grouped 'minority

ethnic communities' together and have failed to recognise difference and diversity within and between communities. These approaches have further reinforced stereotypical narratives for understanding access to services, typically reporting 'lack of knowledge', cultural and religious beliefs, and language barriers among others. The framing of these findings has also typically placed the onus for change on minority ethnic groups themselves rather than services.
Research addressing specific needs of African and African Caribbean people living with dementia is currently minimal, but suggests they are a population least likely to be recognised by services, experience historical discrimination, and significant health inequalities.
We will discuss findings from a recently established steering group of African and African Caribbean older people and people living with dementia to identify research priorities and outline the research co-produced with them. This will examine the experiences of African and African Caribbean people living with dementia across a number of Local Authority sites in England. Taking an intersectional theoretical approach, this in-depth ethnographic study will follow the experiences of a group of African and African Caribbean people living with dementia and their care partners through a series of interviews over time and will also examine how social care staff recognize and respond to the needs of this population. This knowledge is vital to improving services, support the provision of culturally specific services, and to meet the needs of this population.
We argue that rather than aggregating ethnic minority groups together, a focussed approach informed by intersectionality is required to better understand the diverse and complex needs of ethnic minority populations across the UK and Europe.

P13. SPAN+

P13. SPAN+

P13SPAN+: Empowerment for people living with dementia

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Background and aim: Empowerment is seen as a promising concept in dementia care. The aim of our SPAN+ project was (1) to investigate what the concept of empowerment for people living with dementia means and includes, and (2) to develop, and evaluate feasibility and effects, of an intervention that promote empowerment for people living with dementia.

Methods: Based on an interview study, an integrated review and a survey study, we developed an empowerment intervention using intervention mapping. We conducted a feasibility study for the nursing home version and a randomized controlled trial (RCT) to determine effects for the community version. In the project, we used a so-called IMPACT-team consisting of implementation, communication and education experts to ensure the relevance, feasibility and implementability of our intervention.

Results: The identified domains of empowerment: (1) having a sense of personal identity, (2) having a sense of choice and control, (3) having a sense of usefulness and being needed, and (4) retaining a sense of worth, were considered important both at home and in nursing homes, and during different stages of dementia.

The feasibility study showed that, according to healthcare professionals, the program was feasible for promoting empowerment for people living with dementia in a nursing home. The RCT showed no statistically significant effects of the SPAN+ intervention on empowerment, nor on the secondary outcomes measures, for people living with dementia at home and their family caregivers. However, the majority of dyads found the intervention relevant (78%, n=23) and were satisfied using it (92%, n=30).

Conclusion: The SPAN+ study contributes to enabling people living with dementia to according to their competencies, talents and wishes, and family caregivers and healthcare professionals supporting this. During the conference session, we will discuss the project results and elaborate on our IMPACT-team approach.

Innovation in care and research - Assistive technologies

P14. Assistive technologies

P14-01Detecting and diagnosing dementia using digital tools; assessing the views of primary care physicians

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Background: Increasing numbers of people requesting dementia assessment augments the burden on the primary health care system. Digital tools may reduce workload, however, have not yet found their way to daily practice. We aimed to identify facilitators and barriers for the use of digital tools to provide insight into how to implement digital tools in primary healthcare.
Methods: Between June 2023 and February 2024, we conducted a web-based survey among primary care physicians (PCPs) in the Netherlands and Norway. A total of 107 PCPs completed the survey (mean 47 years±SD 11;64(60%) female, years of experience 12±SD 11). The survey consisted of multiple-choice and open-ended questions, i.e., whether they would be interested in using digital tools and why. Based on current literature, facilitators and barriers were listed and categorized into four topics: properties of digital tools, patient characteristics, PCPs own knowledge and implementation in daily practice. PCPs were asked to rank these factors on a Likert scale from very unimportant to very important.
Results: In general, most clinicians (73%) were positive about using digital tools in dementia assessment and follow-up. Figure 1 shows that PCPs often mentioned tools should be easy to understand and provide clear information on validity/reliability. Loss of important information, e.g., clinician's observation, is regarded an important barrier. For their patients, digital tools must be accessible from home and easy to understand. Only few PCPs mentioned their own skills as barrier. For implementation in daily practice, it is considered essential that tools are well integrated in the electronic patient system, support communication and save time. For quotes, see Table 1.
Conclusions: This study showed that most PCPs are positive towards use of digital tools in dementia diagnostics and care. The experienced key facilitators and barriers for adopting digital tools, provide insights for implementing novel technologies in primary care.

Innovation in care and research - Assistive technologies



P14. Assistive technologies

P14-02Assistive technologies in dementia care: new priorities for research and practice

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Introduction: In 2017, an inaugural INTERDEM position paper identified key challenges and priorities regarding assistive technology. The COVID-19 pandemic, rapid development of artificial intelligence, and much groundbreaking research have since re-shaped the field. Members of INTERDEM's Assistive Technology Taskforce therefore studied how challenges from the position paper have been addressed, and identified new challenges emerging. Methods: In addition to an update of a 2017 umbrella review, a Delphi study was performed to better understand experiences, views and priorities of people living with dementia, professional caregivers and informal caregivers. Both studies addressed five aspects of assistive technology: development, usability, (cost-)effectiveness, implementation, and ethics. For the umbrella review, researchers systematically searched four databases and screened results for relevant systematic reviews. Data extracted from included reviews were: characteristics of included studies, results of the review, and review authors' statements related to challenges and priorities. For the Delphi study, the three groups of experts separately ranked the importance of challenges and priorities from the 2017 position paper, and added new challenges and priorities. In subsequent rounds, a consensus ranking was achieved. Results: We will present full results from the umbrella review, including the pooled characteristics of included studies, results of the included reviews, and authors' statements on challenges and priorities regarding technology development, usability, (cost-)effectiveness, implementation, and ethics. Delphi study results will still be pending. Discussion: Based on the presented results, we will discuss the draft priorities for research and practice for 2025-2032. These recommendations will be published in a new INTERDEM position paper in early 2025, integrating results from the umbrella review and the Delphi study. Discussion and debate of draft priorities with conference participants will provide a collaborative approach to help ensure that the final position paper is well-informed, relevant, and impactful in guiding future research and practice.

Innovation in care and research - Assistive technologies

P14. Assistive technologies

P14-03The use of technological interventions by people with dementia and informal caregivers: lessons learned from a field study

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Background: Living with dementia impacts not only the individual but also those around them. Available assistive technology has the potential to contribute to caregiving and relieving the demands on families and services (Astell, et al., 2019). This study captures lessons learned from a field study examining the experiences of people with dementia (PwD) and their informal caregivers using technological innovations at home to support keeping day structure and sleep. This support can contribute to lowering the care burden. Method: One of the aims of the field study was to discover experiences with non-pharmacological interventions to support sleep. These interventions were mostly technological devices, e.g., a hybrid embodied companion with an interaction design and a smart music pillow. Besides that, sensors are used to measure sleep and the indoor environment. The target group was home-living PwD and their informal caregivers, who used the devices for three to four weeks. By means of semi-interviews with the participants and the execution of the field study, we collected lessons learned. Lessons learned are narrative-based based on themes addressed before, during, and after the field study. Results: The lessons learned can be ordered in lessons before, during, and after using the technological interventions. Before, there were privacy concerns that limited recruitment. During the study, it became clear that it can be necessary to regularly check if everything is working (e.g., sensors). Because participants' digital skills are often limited, therefore support is needed. Lessons learned after the study made it clear that technological devices are not always appropriate for the end user because of, for example, a lack of experience with technology or health issues (apathy). Conclusion: Awareness of the health conditions and digital limitations of PwD is needed. Selecting the right technological innovations and providing support before and during use is highly appropriate.

Innovation in care and research - Assistive technologies

P14. Assistive technologies

P14-04Intention to use digital tools in the context of dementia prevention and early Alzheimer's disease: an ABOARD study

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Background: Given the increasing digitalization in health care, it is crucial to get insight into who is able and willing to use digital tools for brain health in the context of dementia prevention and early Alzheimer's disease. The aim of this project is to investigate which characteristics are associated with people's intention to use digital tools for brain health.
Methods: Data was gathered via an online questionnaire among cognitively healthy people or people with subjective cognitive decline on Hersenonderzoek.nl, which covered demographics, digital literacy skills, technology acceptance, perceived dementia risk, behaviour change motivation, net promoter score, and intention to use digital tools. The questionnaire included a use case of an existing Dutch dementia prevention app for citizens (MijnBreincoach). Exploratory correlation analyses have been conducted in SPSS on demographics and final analyses will be conducted via lasso regression.
Preliminary results: Thus far, 507 participants completed the questionnaire (69.8% female, mean age 60.6 years (SD=14.3), mean health literacy 1.72 (SD=0.456) and 26% low educational attainment). Mean intention to use was 2.88 (SD=0.95; scale 1-5) and mean net promoter score was 6.38 (SD=2.44; scale 0-10). Spearman correlation analyses showed a modest positive relationship between educational attainment and intention to use for MijnBreincoach ($r(505)=0.09$, $p=0.037$). No significant association was found for sex, age, health literacy, and financial scarcity, and net promoter score and intention to use MijnBreincoach. We currently collect additional data to enrich sample diversity regarding socioeconomic position, ethnicity, and digital literacy. We expect the data collection to be completed in summer 2024.
Conclusion: Future insights from this study will offer insights into who is able and willing to use digital tools for brain health. This study may thus contribute to inclusive digital tool development and brain health-related care.

Innovation in care and research - Assistive technologies

P14. Assistive technologies

P14-05The ethics of electronic tracking devices in dementia care: an interview study with developers

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Background: The use of tracking devices, such as GPS watches, to mitigate dementia-related wandering risks presents ethical challenges. While much research has focused on end-user perceptions, device acceptability, and the ethical implications of device use, the role of developers has received considerably less attention. This gap exists despite the critical role of design and development on a technology's ethical impact.
Research question: How do developers of electronic tracking devices perceive ethical issues surrounding the design, development, and use of electronic tracking devices within dementia care? Methods: Semi-structured interviews were performed with 15 developers (9 commercial and 6 university) across 9 countries (United States, Denmark, Austria, Germany, Canada, Belgium, United Kingdom, Turkey, Singapore).
Results: Developers expressed strong feelings of moral responsibility towards creating better devices that improve the lives of persons with dementia and their caregivers. They navigated tensions between ethical and non-ethical values in pursuit of moral and technical goals, turning to stakeholder inclusion, organizational mission, and domain experts to help find a balance. Pressures, such as profitability demand, greatly influenced decision-making. In general, developers felt stronger moral responsibility towards areas perceived to be within their control, like designing for privacy, and a weaker sense of moral responsibility towards areas perceived as outside their control, like the actual use of their devices, forming a perceived divide between development and use.

Policy - New funding models for dementia care and research

P15. New funding models for dementia care and research

P15-01ZonMw in dementia research: connect, stimulate, impact

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ZonMw

The Dutch organization for healthcare research, ZonMw, aims to ensure good health for everyone by building and utilizing knowledge. Our dementia programs execute the aims of the Dutch National Dementia Strategy: to treat, diagnose and eradicate dementia and to support people with dementia and their loved ones.

We identify knowledge gaps, provide subsidies for research and innovation, enable and support networks and facilitate the implementation of research findings. The initiatives we fund include large scale partnerships, early-career researchers, implementation projects, social and human-oriented approaches to health care; and practical local initiatives to engage people with dementia in activities. We encourage different types of collaborations: multidisciplinary, international, public-private, daily practice-oriented, and collaborations with end users: healthcare professionals, people with dementia, and their loved ones.

With our subsidies and collaborations we have brought together many independent cohorts to form nine large, currently active, consortia. By bundling their valuable data on different patient populations they can answer important questions, including the prevention, treatment and diagnosis of dementia. Next, we will formally evaluate the consortia's information infrastructures to ensure that all efforts and resources are optimally used to serve the consortia's main aims of generating and implementing knowledge. Next to consortia, we funded 13 currently active projects by early-career researchers, mainly focused on fundamental research, thereby generating crucial knowledge while training the future generation of scientists. Furthermore, implementation subsidies support projects to implement their newly generated knowledge in daily practice. And practical projects facilitate the participation of people with dementia and their loved ones in society and improve quality of life through tailored activities and by evaluating social and well-being-based interventions.

In short, by identifying and addressing knowledge gaps, facilitating collaborations and funding partnerships, we generate and implement knowledge to optimally support people with dementia and their loved ones, and to ultimately eradicate dementia.

Policy - New funding models for dementia care and research

P15. New funding models for dementia care and research

P15-02Using a bottom-up approach to create a grant program

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In 2023, Alzheimer Nederland decided to create more opportunities for quality-of-life research. Rather than offering grant opportunities in an open call or taking a top-down approach for call themes, we used a bottom-up approach. Through various channels, we asked health care professionals and informal caregivers which successful innovations they use for which they were not aware if it had been scientifically proven. These are innovations that currently have a small-scale implementation and could potentially attain a larger impact through dissemination.

At the same time, it is not known what the precise impact is of these innovations in the current settings and what the impact could be in other settings. This innovative grant program creates opportunities to test innovations in new settings in order to learn more about the impact of the innovation.

We received 71 reactions with descriptions of innovations from health care workers and informal caregivers. We categorized them into the following themes: general activities, activities of daily living (ADL), alarms, movement, communication, sleep, scheduling, wandering, sense of self-worth, emotions, affection, poorly understood behavior, informal caregiver stress, personalized care, and other. All responses were evaluated on potential impact and need for scientific assessment. Many responses were deemed logical; therefore, no research was needed. These will be used in our communication channels for the general public.

We defined 2 specific innovations (an app to help attain better sleep patterns and a wellbeing library) and 3 themes (poorly understood behavior during morning care, keeping a healthy weight, and using volunteers for providing care) which need more research. A new committee with a focus on societal impact provided focus for the research topics. Researchers applied for a € 150.000 grant to investigate the value of innovations/innovations within specific themes.

Policy - New funding models for dementia care and research

P15. New funding models for dementia care and research

P15-04The Pasqual Maragall Researchers Programme: boosting excellence in research to defeat Alzheimer's and other related dementias

Carolina Minguillon[1], Lauren Fleming[2], Eva Nebot-Folquer[2], Nina Gramunt-Fombuena[2], Arcadi Navarro[2]
[1]-, [2]Pasqual Maragall Foundation

The huge economic and social cost of dementia, with Alzheimer's being the main cause, and its high prevalence poses one of the greatest challenges for the sustainability of healthcare systems worldwide. With no effective treatment and life expectancy rising, the situation will become unsustainable. From its founding, the Pasqual Maragall Foundation (PMF) firmly believes that advancement in research is the only way to defeat these diseases.

Spain has highly competitive research centres of excellence that already contribute to the global creation of knowledge in this field and constitute a valuable scientific capital. Data from a bibliometric study commissioned by the PMF place Spain as one of the leading countries in research in Alzheimer's and related dementias and endorse its scientific strength in responding to the challenge posed by the approach to these pathologies.

In this context, and to help increase the excellence of the research carried out by national researchers and (international) collaborators, the PMF launched the Pasqual Maragall Researchers Programme (PMRP; https://fpmaragall.org/en/pasqual-maragall-researchers-programme/) in 2022. The PMRP aims to nurture and support translational or clinical research projects focused on Alzheimer's disease or other age-related neurodegenerative diseases. The PMRP funds, with up to 800.000€, individual or collaborative research projects that are executed within a maximum period of five years. The first call received a total of 66 proposals and, after a thorough 2-stage external peer-reviewed process including international renowned experts, a total of 3 proposals were selected for funding. The proposals submitted to the second PMRP call are currently being evaluated. In this presentation, we will (1) summarise the characteristics of the PMRP, (2) analyse the proposals received in the first two calls of the programme, and (3) outline the projects granted through this initiative.

Policy - Dementia work force

P15. New funding models for dementia care and research

P15-05How sustainable is our dementia care?

Jan Steyaert
Expertisecentrum Dementie Vlaanderen

Over the past years, a lot of work has been done to improve the care for persons with dementia and their family caregivers. A lot has been achieved, although a lot can still be improved, both by developing new insights in good dementia care as well as mainstreaming implementation of them.
We however also have to consider how sustainable this dementia care will be over the next years and decades. Two demographic developments endanger that sustainability. On the one hand, the greying of our population is now approaching its peak and the number of persons at old age, and those being 80+ or even 90+, will increase substantially. On the other hand, the population at working age will not increase and in some regions even decrease.
The consequence of these demographic changes will be tremendous. As no substantial plans to build extra nursing homes are in place, more persons with dementia will live at home, often without partner and with more care needs than now. In some countries, like Flanders, the Netherlands and Norway, there is a sense of urgency, but unfortunately no easy pathway to dealing with this issue.
Several possible solutions are mentioned, such as further raising the retirement age or labour migration from outside Europe. And more specific for care: reduction of bureaucracy in care organisations, prevention, technology replacing caregivers, building caring neighbourhoods, … Even the idea of expanding the law on euthanasia is being suggested, with debates on "fulfilled live" in Flanders and the Netherlands.
However complex and unattractive this puzzle of solutions is, we need to solve it to guarantee dementia care will remain available. We need more sense of urgency on this topic, and more sharing information sharing on policy measures taken in different countries.

P16. Alzheimer Switzerland - Living arrangements

P16. Société solidaire des personnes atteintes d'Alzheimer ou d'une autre démence

P16-01Programme de sensibilisation de la police genevoise

Sophie Courvoisier[1], Mikaela Halvarsson[2]
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Aider les personnes en détresse fait partie de la mission de la police. Les personnes atteintes d'Alzheimer ou d'une autre forme de démence se retrouvent souvent en situation d'urgence à cause de leur perception altérée de la réalité. Entendre, voir, goûter, sentir ainsi que s'orienter dans le temps et dans l'espace posent problème et peuvent conduire à des situations à risque qui requièrent l'intervention de la police.
L'arrivée de la police peut représenter une situation de stress pour le malade et le gyrophare ainsi que l'uniforme peuvent être ressentis comme une menace.
Afin de permettre à la police d'intervenir de la manière la plus adéquate possible, il est essentiel de sensibiliser les policiers à cette maladie et de leur donner des conseils pratiques pour que l'intervention ne soit pas vécue comme un traumatisme pour le malade et la famille.
Ce programme de sensibilisation a été mis en place depuis 2017 pour la police cantonale genevoise et il a depuis été intégré dans le programme de formation de l'académie de police qui forme les aspirants des cantons du Valais, de Vaud et de Genève.

P16. Alzheimer Switzerland - Living arrangements

P16. Société solidaire des personnes atteintes d'Alzheimer ou d'une autre démence

P16-02Alzheimer Valais Wallis : Après-midi jeux pour personnes avec trouble neurocognitif accompagnées d'un proche

Valérie Morard Ducrey
Alzheimer Valais Wallis

Lors de cette présentation nous explorerons une offre conviviale pour les personnes malades accompagnées d'un proche : « Après-midi jeux ». Pourquoi jouer ? Quel type de jeux choisir ? Après un bref exposé sur l'organisation de notre prestation, nous mettrons en lumière les bénéficies du jeu tant pour la personne malade que pour le proche et leur relation.

P16. Alzheimer Switzerland - Living arrangements

P16. Société solidaire des personnes atteintes d'Alzheimer ou d'une autre démence

P16-03pARTage - visite au musée

Caroline Qurashi
Alzheimer Vaud

L'association Alzheimer Vaud a développé un programme novateur en formant des médiateurs culturels spécifiquement pour accueillir des personnes atteintes de troubles neurocognitifs. En partenariat avec deux musées, Alzheimer Vaud organise des visites adaptées, où chaque personne est accompagnée d'un bénévole qualifié. Ensemble, ils participent à un cycle de cinq visites, conçues pour offrir un parcours fluide et accessible, parfaitement adapté aux besoins de ce public.

L'art joue un rôle essentiel pour les personnes atteintes de troubles neurocognitifs. Ces visites spécialement encadrées permettent non seulement de les stimuler, mais aussi de favoriser le dialogue. À leur arrivée, les groupes de participants sont accueillis par une médiatrice des musées partenaires. Ils sont accompagnés par leurs proches aidants ou par nos bénévoles, pour une exploration des œuvres d'art dans un cadre chaleureux et bienveillant.

Chaque visite se déroule dans une atmosphère propice aux échanges, où les participants peuvent partager leurs impressions et ressentis. Ces moments d'interaction sont précieux, car ils permettent de renforcer les liens sociaux et d'encourager l'expression personnelle à travers l'art.

La visite se termine par un moment de convivialité autour d'une collation, offrant ainsi une opportunité supplémentaire de partage et de détente. Fort de ce succès, Alzheimer Vaud aspire à élargir son réseau de musées partenaires pour permettre à un plus grand nombre de personnes de bénéficier de cette expérience enrichissante.

En alliant art, culture et soutien personnalisé, ces visites contribuent à améliorer la qualité de vie des personnes vivant avec des troubles neurocognitifs, tout en leur offrant des moments de plaisir et de découverte.

P16. Alzheimer Switzerland - Living arrangements

P16. Société solidaire des personnes atteintes d'Alzheimer ou d'une autre démence

P16-04Projet des soins anticipe par procuration pour les personnes n'ayant plus la capacite de discernement : résultats d'une étude pilote

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Introduction : Il a été démontré que le Projet des soins anticipé (ProSA) favorise des soins conformes aux souhaits du patient, mais le maintien de la capacité de prise de décision (CPD) est une condition préalable à l'application des modèles traditionnels du ProSA. D'autres modèles de ProSA sont nécessaires pour être utilisés avec et au nom des personnes qui n'ont pas ou plus la capacité de prendre des décisions medicales. Nous avons développé un modèle de ProSA par procuration (ProSApp) spécifiquement destiné aux résidents d'établissements de soins pour personnes âgées (EMS) qui n'ont plus la capacité de prendre des décisions.

Objectif : tester l'acceptabilité et la faisabilité de cette intervention de ProSA PP à travers une étude pilote

Méthode : La collecte des données s'est déroulée dans quatre RACF de Suisse romande. Les facilitateurs du ProSA pp ont participé à des entretiens semi-structurés et ont rempli une échelle numérique d'auto-efficacité (1 : pas du tout confiant, 10 : très confiant) avant (n=14) et après (n=4) l'achèvement du ProSApp. Les représentant thérapeutiques de résidents ayant plus leur capacité de discernement ont participé à un entretien semi-structuré et ont rempli l'échelle de conflit décisionnel. Les entretiens ont été retranscrits mot à mot et analysés de manière thématique.

Résultats : Les facilitateurs et les représentants thérapeutiques ont déclaré que l'intervention était utile. Le conflit décisionnel du représentant thérapeutique a diminué de manière

significative et l'auto-efficacité du facilitateur s'est augmenté. De nombreux facteurs menaçant la faisabilité de l'intervention ont été identifiés.

Discussion : Alors que les professionnels de santé des RACF et leurs supérieurs étaient enthousiastes à propos de ProSApp, la mise en œuvre de ProSApp est complexe en raison du contexte des EMS et de la rotation du personnel.

P16. Alzheimer Switzerland - Living arrangements

P16. Société solidaire des personnes atteintes d'Alzheimer ou d'une autre démence

P16-05L'essentiel du conseil spécialisé d'Alzheimer Suisse

Agnes Henry
Alzheimer Suisse

Un aperçu de l'activité du conseil spécialisé d'Alzheimer Suisse. Quelques chiffres, objectifs et exemples du quotidien.

Patient pathways - Treatment and medical management

P17. Treatment and medical managemement

P17-01Findings of the realist, mixed methods, longitudinal evaluation of the D-PACT (dementia personalised care team), primary care based, post-diagnostic, dementia care model

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University of Plymouth

Background: Various dementia support roles exist in the UK and internationally. Role remits vary and impact evidence is limited. While consensus that post-diagnostic dementia support should be located within primary care is building, there is little guidance on what this model should look like. The Dementia PersonAlised Care Team (D-PACT) project addressed these evidence gaps by developing and evaluating a primary care-based model of post-diagnostic support. The model focuses on the ongoing delivery of personalised care - attending to what matters most to people with dementia and unpaid carers, improving practitioners' collaborative working and promoting anticipatory care/planning. Methods: A mixed method, longitudinal, realist evaluation. The model was delivered in a range of rural, coastal and urban locations across England to 125 people with dementia and 121 unpaid carers. Data included: 112 interviews with people with dementia and/or unpaid carers, 48 DSW interviews; 9 recorded surgery feedback sessions; observations of 50 DSW-client interactions and 14 supervision meetings, and 103 electronic medical records of people with dementia. The realist case study analysis attended to the model's underpinning mechanisms, its impact and what contextual factors affected the degree of change it generated.
Findings: Most carers and/or individuals with dementia reported positive experiences of support provided, with many describing psychological, physical or social changes. Contextual factors included: DSWs' contracted hours; access to patient medical records, communication skills (person centred and multi-lingual) and expertise in dementia (acquired through personal and work experience). Whether positive change was achieved early on; how various forms of support were provided to DSWs, and the ability and desire of other professionals to collaborate with them also affected how well the model worked.
Conclusion: Ongoing post diagnostic, personalised dementia care from a support worker, supervised by a specialist dementia practitioner, can increase timely disclosure of patient concerns, and improve risk management.

Patient pathways - Treatment and medical management

P17. Treatment and medical managemement

P17-02"It's an isolating experience to not be able to communicate": a qualitative study on the management of co-existing dementia and hearing loss in social care settings

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Background: Dementia and hearing loss are highly prevalent and increase in prevalence and severity with age. Among certain populations, for example in care homes, the vast majority of people live with one or the other condition, and many live with both. Hearing loss is often overlooked in people living with dementia, resulting in under-diagnosis and lack of appropriate management. The presence of both conditions can mask each other, presenting challenges for both diagnosis, treatment and support; living with both conditions can increase care burden. Aim: To qualitatively investigate the challenges experienced delivering patient-centred care for people living with co-existing dementia and hearing loss (PLWDHL) in social care settings. Methods: Four focus group discussions comprised of seven social care professionals, and six informal carers and one PLWDHL, focussed on two areas: i) the experience of caring PLWDHL and ii) the challenges of delivering patient-centred care to PLWDHL. Data were analysed using reflexive thematic analysis described by Braun and Clarke. Results: Six themes were identified: i) inclusion of PLWDHL; ii) benefits and challenges of communication, iii) hearing aids, iv) complication of masking conditions, v) standardisation of care services and vi) training of care staff. The lack of formal training on hearing aid maintenance was identified as a barrier to appropriate care for PLWDHL, contributing to the low use of hearing aids in care homes. Lack of appropriate strategies to support PLWDHL to participate in daily activities resulted in their exclusion, contributing to social withdrawal and isolation. Conclusion: The findings highlight the need for comprehensive training for social care professionals to help support the management of hearing loss in people living with dementia. Individuals living in social care should be reviewed regularly to ensure that care needs are adapted to suit the progressive nature of the conditions.

Patient pathways - Treatment and medical management

P17. Treatment and medical managemement

P17-03Examining the risk of developing dementia in late-life depression treated with antidepressants: insights from a nationwide population cohort study

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Background: Antidepressants are commonly prescribed for depression in individuals with dementia, and late-life depression has been linked to an increased risk of subsequent cognitive decline or dementia. However, the precise relationship between antidepressant use in late-life depression and the development of incident dementia remains relatively unexplored. Methods: Employing a population-based retrospective cohort design, we accessed data from the Taiwan National Health Insurance Research Dataset spanning 1998 to 2013. Our focus was on individuals newly diagnosed with depression between 2000 and 2007, excluding those with prior antidepressant treatment or below 60 years of age. The primary endpoint was incident dementia occurrence, with the time from antidepressant prescription or depression diagnosis until the event or study conclusion in 2013 as the time to event. A total of 563,918 cases were analyzed, categorized into antidepressant users or nonusers, and assessed using Cox proportional hazards models to determine hazard ratios and 95% confidence intervals. Results: Our findings revealed no significant increase in dementia risk associated with antidepressant exposure among late-life depression patients, irrespective of dosage levels. Both low and high exposure dosages exhibited hazard ratios close to unity, indicating no substantial effect on dementia incidence. Sensitivity and subgroup analyses further validated these results, underscoring their robustness. Conclusions: Our study indicates that antidepressant use does not heighten the risk of incident dementia in individuals with late-life depression. These findings provide reassurance regarding the safety profile of antidepressants in this context and offer valuable insights for clinical decision-making.

Patient pathways - Treatment and medical management

P17. Treatment and medical managemement

P17-04Accessing and navigating systems of care for dyads living with dementia alongside other long-term conditions in the UK: a realist review

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Globally, systems of care struggle to support people living with dementia alongside other long-term conditions. Contact with services and self-management of conditions are often carried out as a dyad (person and supporter), and both may be living with additional health and care needs. The current organisation of services inhibits professionals' abilities to respond to co-occurring, sometimes contradictory needs, and rarely considers the implications for the dyad. This presentation focuses on the findings of a realist review (part of a larger study (NIHR158147)) on how health and care systems enable (or not) dyads living with dementia alongside other long-term conditions to access and navigate support. Ethical approval was obtained (ref 23/LO/0829). To inform searches and data extraction, existing theories on supporting people living with multiple long term conditions and dementia from 28 influential studies were mapped to the NHS Well Pathway for Dementia. In total, sixty-three empirical studies and interviews and workshops with 30 stakeholders refined these to seven programme theories that could explain how dyad, service and system factors can increase or ameliorate the burden of care and diagnostic overshadowing. Financial constraints and devolved responsibilities across organisations and the workforce increased the burden of dyads for keeping well and maintaining continuity of care across unconnected services. The capacity of the dyad to cope with this work, particularly as dementia progressed, was linked to their sense of agency during encounters with services and how responsive services were to their needs. Where confidence in a service broke down, this led to a reluctance to engage, further exacerbating burden. These findings are guiding modelling work to simulate system changes (both minor and major) that improve outcomes and resource use for people and their families living with dementia alongside other conditions.

Patient pathways - Treatment and medical management

P17. Treatment and medical managemement

P17-05Prescription of analgesics and psychotropic medication in older Norwegians with/ without dementia during the COVID-19 pandemic: a HUNT study

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Background: Findings on how the COVID-19 pandemic affected medication prescription among older adults are conflicting. Aim: To track changes in prescription rates and dispensed daily dose (DDD) of analgesics and psychotropic medication in older Norwegians during the pandemic and examine whether changes varied according to dementia status. Methods: We linked baseline data for 10,464 participants (54% women, mean age 76 years [SD 5.8]) from the Norwegian Trøndelag Health Study (HUNT4 70+) with the Norwegian Prescription Database. Age, sex, and education adjusted Poisson regression was applied to examine changes in prescription rates, and multilevel mixed-effects linear regression was used to estimate mean DDD during lockdown (March-September 2020), compared with corresponding months one year prior (2019) and two years after (2021 and 2022) lockdown. Results: Prescription rates increased for opioids from lockdown to 2022, and for other painkillers, from 2019 to 2022. Mean DDD for other painkillers increased during the same periods. For anxiolytics/sedatives the mean DDD was higher in 2022 than during lockdown. There were no changes for antidepressants or antipsychotics. When stratified by dementia status, individuals without dementia had an increase in mean DDD for other painkillers from 2019 to 2022, and a higher mean DDD for antidepressants in 2021 and 2022 compared to lockdown. There were no changes among those with dementia. Conclusion: Two years after lockdown, we found an increase in prescription rates for analgesics, and in mean DDD for anxiolytics/sedatives and antidepressants. Besides the utilization of analgesics for COVID-19 symptoms management, the increase in prescription rates for analgesics may relate to a reduction in nonpharmacological interventions for pain treatment during the pandemic. Coupled with the increase in mean DDD for some psychotropic medications, these findings underscore the need for enhanced monitoring of individuals already vulnerable to pain and psychological strain in situations like a pandemic.

Living with dementia - Art and dementia

P18. Art and dementia

P18-02Prospective Exploration of the Impact of Dance (DIT-DIT) on patients with Alzheimer's disease: quality of life, functionality, and cognition

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Background: Dementia, especially Alzheimer's disease (AD), poses a growing challenge to public health. As research focuses on early diagnostic strategies, non-pharmacological therapies like dance are gaining interest. This prospective observational study aims to assess and confirm previous pilot Study results from our center regarding the impact of dance on AD patients, exploring quality of life (QoL), functionality, and cognition.
Methods: Participants were randomly selected from the Ace Alzheimer Center Barcelona day-care facility for an interventional study. The evaluation commenced in February 2024 and will conclude in July 2024, with dance sessions (DIT-DIT) conducted twice per week throughout this period. Demographic data and variables will be assessed using questionnaires and standard scales to explore the impact of dance on quality of life (QoL), functionality, and cognition. Statistical analyses will compare pre- and post-intervention measures to determine effectiveness.
Results: A total of 21 individuals (mean age: 82 years; 76% female) diagnosed with dementia have been enrolled in our ongoing study. Prior, a preliminary pilot study demonstrated significant correlations between DIT-DIT sessions and improvements in QoL and functionality. Although overall QoL scores remained unchanged, subjective enhancements were observed. Increased session frequency improved functionality, particularly balance (Berg's test). Some participants showed enhancements in MMSE and ADAS-Cog. Correlations were identified between age and changes in QoL, session frequency, and alterations in balance and activities of daily living (ADL), as well as between changes in QoL and ADL. Moreover, a positive correlation was observed between changes in these activities and MMSE scores. The ongoing study is slated for completion in July 2024.
Conclusions: Although subjective and objective improvements in quality of life, functionality, and cognition related to dance were observed, study limitations underscore the need for more extensive and rigorous future research. Dance, as part of a comprehensive approach, could offer holistic benefits to dementia patients.

Living with dementia - Art and dementia

P18. Art and dementia

P18-03Il Manto - The art of care

Alessandro Manzella
ACSI Teatro Sociale

Il Manto - The art of care is a theatrical performance that questions the art of care and is part of a path of cultural welfare to promote active and creative participation of people in a condition of fragility. The show, about an hour long, debuted for the City hall of Milan in 2022.
What is the role of the elderly in our society? Is there a recipe to age well from a young age? How does the body change? We try to answer to some of the questions through the props and stories that emerged from a social theatre and community workshop for and with a group of adults, seniors and caregivers that took place during some Alzheimer's Cafes in Milan. The scripts, also available in English, were written by a member of the group, a woman who for more than seventeen years accompanied and assisted her sister in her illness, from the diagnosis of Alzheimer's to the end. Some of the participants are on stage, in detail six women +75 and a man +80, together with a dancer and a professional musician. With the aim of relaunching creativity and unexpressed psychophysical resources and promoting self-confidence and interpersonal relationships, we propose a performance that reflects on the themes of aging, dementia and the matter of who takes care of the people that take care of others. The title of the show is inspired by the work of Piero della Francesca La Madonna del manto where the mantle metaphorically represents the figure of the caregiver who embraces and protects. This show encourages to look to old age overcoming the concepts of health and disease, starting from the strength and wisdom of the age to rebuild the intergenerational bond.

Living with dementia - Art and dementia

P18. Art and dementia

P18-05Bringing the creative into everyday life: supporting family members living with dementia to engage with music and improvised movement via online video meeting

Jennifer England
University of the Highlands and Islands, Scotland

Background: Music has been shown to have multiple benefits for persons living with dementia (PLWD) but there appears scarce research in combining this with improvised movement to support creative expression and relational connection for 'dementia dyads' (a PLWD and a significant other in their life). Music interventions have primarily focussed on the perspective of the PLWD whilst this research takes a dyadic view in both considering well-being and musical preference. This paper reports on phase 1 of a larger study, drawing on two case studies of dyads participating in individualised music and movement sessions via online video meeting.
Aims:To explore:

- the experience for the dyad
- the viability of facilitating the activity via video meet
- the sustainability of the activity without facilitator input

Methods: A longitudinal qualitative study using thematic analysis. Each dyad participated in individually tailored weekly sessions with the researcher via Teams meeting; dyad 1 for 6 months, dyad 2 for 2 months. Data was collected through video recordings and interviews. Initial thematic findings were further developed in a collaborative process with participants.
Findings: The combination of music and movement offered intimate playful time together, reciprocal engagement, joyful expression, and agency. Musical choices that inspired both persons maximised enjoyment, movement and sustainability. The online model enabled creative expression in a safe, familiar environment. Recording meetings was unobtrusive and enabled short videos to be later shared with the dyad, with the added benefit of offering the family unique memories. Hindrances were disorientation moments looking at the screen and quality of sound.
Discussion: This a viable model to support dyads to share meaningful creative time together. More use can be made of videos to support memories of and re-engagement with the activity.

P19. INTERDEM Advances in social health, brain health and methodological research of psychosical interventions in dementia care

P19. Advances in social health, brain health and methodological research of psychosocial interventions in dementia care

P19-01Dementia risk reduction in the Netherlands: overview of intervention and implementation studies

Kay Deckers
Maastricht University / Alzheimer Centrum Limburg

In the Netherlands, there are several (ongoing) initiatives in the field of dementia risk reduction. In this presentation, we will highlight four of them: FINGER-NL, 'We are the medicine ourselves', PRIMA-Brain and LIGHT.

FINGER-NL is a multi-center, randomized, controlled, multidomain lifestyle intervention trial among older 1210 Dutch adults at risk for cognitive decline, with a duration of 24 months. Recruitment started in January 2022 and was completed in May 2023. Baseline lifestyle and clinical measurements showed successful recruitment of participants with sufficient potential for prevention. The last participant's, last visit is expected in June 2025.

'We are the medicine ourselves' is a health promotion campaign aimed at increasing awareness about dementia risk reduction in middle-aged community-dwelling individuals. Between 2018 and 2024, the campaign successfully ran in eight municipal health regions in the Netherlands. In 2025, a booster campaign will be launched with a special focus on individuals with a migration background and individuals with a low socioeconomic status.

PRIMary care App-supported Brain health promotion (PRIMA-Brain) is a proof-of-concept cluster-randomized trial investigating the feasibility of a three-month-long blended brain-health promotion intervention in primary care. 188 participants (40–60 years), with modifiable dementia risk factors were included from ten Dutch general practices. Both quantitative and qualitative data showed that integrating dementia risk reduction in primary care, supported by a smartphone app, is a viable approach towards dementia risk reduction.

Lifestyle Intervention in the memory clinics of General and academic Hospitals Trial (LIGHT) is a 12-month multicentre randomized controlled trial investigating the effects of an innovative lifestyle intervention compared to usual care. Starting in summer 2024, the trial aims to include 300 older adults (≥ 50 years) with subjective

cognitive decline and mild cognitive impairment who have ≥2 modifiable dementia risk factors from the memory clinics of Maastricht UMC+ and Amsterdam UMC.

P19. INTERDEM Advances in social health, brain health and methodological research of psychosical interventions in dementia care

P19. Advances in social health, brain health and methodological research of psychosocial interventions in dementia care

P19-02Precision prevention for dementia in an integrated care setting for neurodegenerative diseases in Luxembourg

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The "Programme Dementia Prevention" (*pdp*) is based on scientific evidence for prevention of dementia by addressing specific modifiable risk factors, which account for up to 40% of all dementia cases (Livingston et al., 2020). The pdp targets individuals at risk to develop dementia with mild cognitive impairment (MCI) or subjective cognitive decline (SCD) by (i) identifying target groups, (ii) defining individual profiles of modifiable risk factors, and (iii) offering multi-domain interventions tailored to each participant through a multidisciplinary network (Schröder et al., 2024). In the core of pdp are memory coaches that after comprehensive neuropsychological testing, define individual risk profiles and enables precision prevention by attributing vouchers for specific preventive interventions to reduce the risk profiles of each participant. With now more than 600 participants (as of April 2024) included in the programme, the *pdp* is actively expanding also thanks to an increasing number of referring physicians. Recently the emerging need for integrated care for people with neurodegenerative diseases in Luxembourg translated into the launch of the first “Réseau de compétences maladies neurodégénératives (RdC) - ParkinsonNet Luxembourg”. The RdC is based on a pilot phase of more than 5 years focusing on multidisciplinary care for Parkinson’s disease (PD) including continuous medical education for healthcare professinoals. The unique expertise developed within the *pdp* and the scientific evidence for early cognitive impairment in PD make the *pdp* perfectly positioned to contribute integrate precision prevention in the RdC. Therefore, the *pdp* will continue to be highly relevant for addressing unmet needs for public health in the Luxembourgish population.

P19. INTERDEM Advances in social health, brain health and methodological research of psychosical interventions in dementia care

P19. Advances in social health, brain health and methodological research of psychosocial interventions in dementia care

P19-03Social health as a framework for exploring inequity and intersectionality in dementia care

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[1]Dublin City University, [2]

Individual characteristics, geographical, socioeconomic, ethnic, gender, and educational disparities hinder access to and utilization of care services for individuals and caregivers, leading to inequities in dementia care and research. Prevailing interventions are often generic, neglecting individual differences and resulting in limited effectiveness. The implementation gap exacerbates these challenges by impeding the integration of evidence-based models and interventions into routine care practices. Barriers such as time constraints, inadequate training, and lack of policy hinder the widespread adoption of effective care practices.

A social health framework provides a comprehensive lens to explore and address inequities in dementia care. Social health encompasses the interplay between individual, community, and societal factors that influence health and well-being. By considering the social determinants of health, such as socioeconomic status, education, access to healthcare, and social support, a social health approach can identify the root causes of disparities in dementia care and develop targeted interventions. Furthermore, an intersectional perspective recognizes that individuals' experiences are shaped by the interaction of multiple social identities and systems of privilege and oppression. Applying an intersectional lens to dementia care research and practice can reveal how various social factors, such as race, gender, and age, intersect to create unique challenges and barriers for diverse groups of people living with dementia and their caregivers.

The JPND-funded INTEREST (INnovaTions in divERsity and Equity in Social health research in DemenTia) working group aims to address health care disparities and inequities in dementia care and research by: (i) Developing strategic policy and best practice guidelines to address inequities in dementia care; (ii) Creating research frameworks and methodologies for transdisciplinary research focused on diverse groups of people with dementia; and (iii) Building research capacity to better understand and address the social determinants of health in dementia care.

P19. INTERDEM Advances in social health, brain health and methodological research of psychosical interventions in dementia care

P19. Advances in social health, brain health and methodological research of psychosocial interventions in dementia care

P19-04Translation of evidence of integrated human and mice studies into new targets for preventive social health interventions

Myrra Vernooij-Dassen[1], van der Velpen Isabelle[2], Suzanne Lanooij[2], Meike Vernooij[2], Mohammed Arfan Ikram[2], Uli Eisel[2], Eddy van der Zee[2], Martien Kas[2], Marieke Perry[2]
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Prevention of dementia is considered a healthcare priority. However, there are there are few effective preventive interventions. There is an urgent need to find new avenues to prevent dementia and optimally use the capacities of people with MCI. Social health is increasingly known to play a role in the development of cognitive decline and dementia. 'Social health' is a relational concept in which well-being is defined as the mutual impact that an individual and the social environment have on each other.

We aimed to study the relationship between social health and brain health to identify new targets for interventions.

Therefore, we integrated the results of our SHiMMy (Social Health in Mice and Men) project in which human epidemiological and qualitative studies and mapping and experimental mice studies to derive intervention targets. Our epidemiological studies demonstrated associations between social health (marital status, perceived social support,

and loneliness) and brain structure (including total brain volume, white matter volume and white matter microstructural integrity). Integrated with the qualitative studies, these findings confirmed the key role of a partner as well as the value found in being meaningful within the social environment and reciprocated social support. The experimental mice studies showed that the structure of the social environment impacted brain health. The rodent study added a neurobiological substrate explaining this relationship, by showing an overlap between the cognitive and social domains in the brain. Loneliness and perceived social support were identified as key modifiable social health markers representing potential targets for intervention.

The main conclusions of rodent and human studies are in line with each other, showing that social health may impact brain health, which stresses the need to focus on social health in dementia prevention efforts. The identified targets for interventions can be applied in daily social interaction, clinical practice and public health.

P19. INTERDEM Advances in social health, brain health and methodological research of psychosical interventions in dementia care

P19. Advances in social health, brain health and methodological research of psychosocial interventions in dementia care

P19-05Designs and methodologies to develop, evaluate, and implement psychosocial interventions in dementia: discussing gaps and advancing the field through the METHODEM project

Sara Laureen Bartels[1], Federica D'Andrea[2], Maud Graff[2]
[1]Maastricht University, [2]

The UK Medical Research Council (MRC) Framework emphasizes the importance of developing, evaluating, and implementing interventions based on theory (e.g., implementation science), practice knowledge (e.g., what works or not), and lived experience involvement (e.g., preferences, values, co-approaches) (Skivington et al., 2021). In some research studies in the field of dementia, novel methodological approaches are emerging that are closer to the real world and acknowledge the value of involving people with dementia, unpaid carers, and other stakeholders. The MRC framework has scope to guide approaches and advance psychosocial dementia research. However, it is currently unclear which designs

and methodologies frequently used in psychosocial dementia research address which questions, core elements, or relate to particular phases.
Prof Maud Graff will present the background and focus of the INTERDEM Methodology Taskforce and its METHODEM project (2024-2026), aiming at providing a comprehensive overview of which (novel) designs and methodologies are being used in psychosocial interventions research in dementia; and at reaching a consensus on which designs and methodologies a) integrate the core elements of the MRC framework and b) suit the objectives of each phase in this area best (i.e., which design/methodology is suitable when, how, and why). Following, Dr Federica D'Andrea will discuss some methodological gaps in psychosocial intervention research in dementia, with a specific focus on stakeholder-informed research and co-approaches as well as theory-driven evaluation. Finally, Dr Sara Laureen Bartels will dive deeper into the methodological approaches within the METHODEM project, namely the research plans for an extensive systematic review and Delphi study.
Overall, this session will highlight methodological concerns as discussed by INTERDEM Methodology Taskforce as well as concrete future plans to advance methodologies in the field of psychosocial interventions for dementia.

Inclusion and intersectionality - LGBTQ+

P20. LGBTQ+ community

P20-01Using Photovoice to explore the experiences of LGBTQ+ people living with dementia

John Hammond
Brighton and Sussex Medical School

Background: Historically, studies have either excluded the voices of LGBTQ+ people living with dementia or relied on semi-structured interviews to engage them within research to elicit knowledge on their experiences of dementia and how they can be supported to live well. Research has lacked creative approaches for LGBTQ+ people to tell their stories. This presentation provides insights and recommendations when using the visual research method 'Photovoice' with this minoritised population.
Method: As part of a PhD project, a pilot study was conducted with five LGBTQ+ persons living with dementia using the research method 'Photovoice'. Participants took photographs over a 4-week period of images that represented their experiences of living with dementia and provided short explanatory narratives of the meaning and importance of them. At the

end of the study, participants were interviewed individually about their experiences of taking part in this study and attended a focus group to discuss their experiences with other participants.
Findings: This study highlighted the potential that creative methods such as 'Photovoice,' which draw on Participatory Action Research methodologies, may offer when engaging with LGBTQ+ persons living with dementia. The findings suggest that LGBTQ+ would welcome sharing their experiences of living with dementia and embrace methodologies that enable them to take control of their narrative and leave a lasting legacy for future generations. Furthermore, using Photovoice empowered participants to challenge creatively the stigmatizing societal narratives around dementia and LGBTQ+ identities that they had experienced. The findings have informed the development of a subsequent novel, longitudinal Photovoice study.
Conclusion: Creative methodologies such as 'Photovoice' are a valuable tool for ensuring the voices of LGBTQ+ people are heard within the dementia care agenda. However, it is essential that they are employed in a way that facilitates the engagement of LGBTQ+ people and empowers them to tell their story.

Inclusion and intersectionality - LGBTQ+

P20. LGBTQ+ community

P20-02Speak out with dementia: harnessing the power of online peer support for LGBTQ+ individuals

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[1]Self, [2]Alzheimer's Society of the United Kingdom, [3]Brighton Sussex Medical School

This abstract explores the profound impact of online peer support groups, specifically focusing on Speak Out With Dementia, a community dedicated to LGBTQ+ individuals living with dementia. Amidst the complexities of navigating both dementia and diverse sexual and gender identities, this virtual sanctuary emerges as a beacon of understanding, solidarity, and empowerment.
Speak Out With Dementia provides a safe space where members can share experiences, challenges, and triumphs without fear of judgment or discrimination. Through the exchange of empathy, knowledge, and practical advice, participants find solace in knowing they are not alone in their journey.
The unique intersectionality of LGBTQ+ identities and dementia presents distinctive

challenges, from issues of identity preservation to accessing culturally competent care. Speak Out With Dementia addresses these concerns head-on, fostering a sense of belonging and validation crucial for mental well-being.
Moreover, the online format offers unparalleled accessibility, transcending geographical barriers and providing support to individuals who may otherwise feel isolated. In doing so, Speak Out With Dementia exemplifies the transformative potential of digital communities in fostering resilience and camaraderie among marginalized groups.
Ultimately, the value of Speak Out With Dementia lies in its ability to amplify voices that have long been marginalized, offering a platform for mutual support, advocacy, and empowerment in the face of dementia's challenges. As society strives for inclusivity and equality, initiatives like Speak Out With Dementia serve as a testament to the power of community in overcoming adversity and fostering resilience.

Inclusion and intersectionality - LGBTQ+

P20. LGBTQ+ community

P20-03Transgender and gender diverse older people: health, ageing and dementia

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Background and Objectives: 262,000 people in the UK identify as transgender and gender diverse (TGD), and this population is believed to be growing. As the population is ageing, an increase in older TGD people accessing health and social care can be anticipated. Despite a recent expansion in research exploring the TGD population, older TGD people are often excluded from the narrative. This review aims to address gaps in the literature by exploring the complex ways older TGD adults access health and social care and how this affects health outcomes with a specific focus on dementia.
Methods: The search was conducted using NUsearch, CINAHL, PsycINFO, PubMed, Google Scholar, and MEDLINE, in addition to cross-referencing and hand searches. Data were analysed in a narrative, exploratory manner.
Findings: Older TGD adults face many barriers when accessing health and social care including experiences of discrimination, gatekeeping by healthcare professionals and limited access to services. These barriers impact on health outcomes in this population and their interactions with the health and social care system. There are high reported rates of poor

physical and mental health, including HIV, mental illness and issues associated with gender-affirming treatment. Older TGD people are also reported to be at an increased risk of dementia, which is partly due to high incidences of dementia-associated risk factors. The epidemiology and experiences of older TGD people living with dementia are largely unknown due to limited research. However, the available literature suggests the current health and social care system is ill-equipped to manage their needs.
Conclusion: Greater research exploring the major health problems faced by this population is needed, to address health inequalities. Several approaches have been suggested to help improve services for older TGD people including, expert patient programmes, co-production, and a systems approach.

Inclusion and intersectionality - LGBTQ+

P20. LGBTQ+ community

P20-04What if mine is the last voice? Reflections from a queer person of colour living with dementia

Patrick Ettenes
LGBT Foundation / Bring Dementia Out

Introduction: Hearing the voices of people living with dementia is fundamental for researchers, policy makers and dementia care professionals if they are to have an understanding of what it is like to live with this condition, and to develop dementia services to ensure the highest quality of care.
My background: For over 10 years, I have been advocating for LGBTQ+ people living with dementia and raising awareness of the specific and individual concerns of what it means to live with dementia as a sexual or gender minority.
Concerns for the future: Also for 10 years, I have been the only 'voice' of a queer/non binary person of colour living with dementia. I have regularly presented both in the UK and internationally and won awards (National Diversity Awards 2019, Attitude Pride Award 2021), but I have remained the only lived experience 'voice' speaking of the intersection of LGBTQ identity, ethnicity and age.
Questions and reflections to explore in this presentation: What will happen when I no longer have a voice as my symptoms of dementia progress? Where are the voices of other minoritised ethnic and gender diverse people living with dementia? Has my advocacy work made any difference to the lives of other people living with dementia? What if I am the only

and the last voice of my generation speaking of the intersectional needs of queer people of colour living with dementia?

Inclusion and intersectionality - LGBTQ+

P20. LGBTQ+ community

P20-05Understanding behavioral symptoms of dementia to create dementia-friendly cities and communities

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Objective: To share best practices of initiatives taken by age-friendly cities and communities to be more inclusive to people living with dementia and connect these practices to the GCAD work on the lived experiences of people from historically underrepresented populations, specifically LGBTQ+, Black, Hispanic/Latino, and Asian communities to identify how these journeys can help make these initiatives more inclusive.
Background: GCAD has researched best practices and initiatives taken by age-friendly cities and communities to be more inclusive to people with dementia to showcase steps other cities and communities can take. As part of this research, GCAD connected these practices to its work on the lived experiences of people from historically underrepresented populations, specifically LGBTQ+, Black, Hispanic/Latino, and Asian communities, to identify how these experiences can help to improve the work done by age-friendly cities and communities.
Methodology: To gather insight into the best practices of age-friendly cities, GCAD undertook qualitative primary research complemented by a virtual roundtable to collect case studies.
Results: Results account for an overview of best practices in age-friendly cities in connection to GCAD's previous work on the lived experiences of people from historically underrepresented populations, specifically LGBTQ+, Black, Hispanic/Latino, and Asian communities, identifying how these experiences can help to improve the work done by age-friendly cities and communities.
Conclusion: Through the WHO Network of Age-Friendly Cities and Communities, much work has been done to make cities and communities more inclusive to older people, including those living with dementia. However, there is still much to be done, especially when it comes to recognizing and including behavioral symptoms of dementia in initiatives to be more dementia friendly. The research showcases successful best practices and

concludes with a call to action that encourages cities and communities to take these learnings and become more inclusive to people living with dementia.

P21. PreTAD consortium: Prediction of Alzheimer's Dementia - Today and Tomorrow

P21. PreTAD consortium: Prediction of Alzheimer's Dementia - Today and Tomorrow

P21Prediction of Alzheimer's dementia - today and tomorrow

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In Alzheimer's disease (AD), the constant improvement of risk estimation even in healthy persons or blood tests which may potentially replace the more invasive methods such as CSF and PET foster a paradigm shift from symptom-based diagnostics and therapy to predictive risk estimation and prevention. This predictive turn does not only raise hopes for prevention and anticipating care. It also affects health care systems, and societies. These effects have not been exhaustively assessed so far. While predictive testing can offer opportunities regarding life planning and preventive options, it may also come with psychological burden, stigmatization and discrimination. Moreover, it may impact the fundamental understanding of the concepts of disease, risk and health. Proper information and disclosure reporting obligations, the quality and accuracy of risk prediction, as well as liability for shortcomings have to be adjusted. Regarding those health care systems which are based on solidarity questions arise concerning access to prediction and dealing with scarce

resources.
For the first time, the two consecutive projects PreDADQoL and PreTAD examine individual needs in relation to health services, their perspectives towards risk estimation, and the decision parameters for or against. PreTAD includes individuals with SCD (subjective cognitive decline), individuals with family history of AD or APOE4 allele carriers, and the general population.
The empirical findings are analyzed from an ethical, clinical, linguistic and legal perspective. Given the absence of comprehensive guidelines these findings will inform a framework for clinical practice of predictive testing, including not (yet) cognitively impaired persons.
Results from all subprojects will be presented, highlighting the following topics:
1) The Future of Clinical Care: From Doctor to Oracle?
2) Knowing the Risk - What People Don't Want to Know
3) Let's talk about AD – And What We Learn from it
4) Information, Safety, Equity: Legal Aspects of Prediction

Innovation in care and research - Dementia registries

P22. Dementia registries

P22-01Understanding non-participation of research volunteers from online registries in multi-domain lifestyle interventions: a cross-country comparison

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BACKGROUND: Non-participation impacts the external validity of randomized control trials (RCTs). In two large multidomain lifestyle RCTs to prevent cognitive decline – BetterBrains (online, Australia) and FINGER-NL (hybrid, the Netherlands) – we aimed to clarify socio-demographic, medical and lifestyle contributors to (non-)participation in such trials. METHOD: 5,375 adults (69% female) aged 60-79 years enrolled in the Dutch Brain Research Registry(DBRR), and 5,193 adults (74% female) aged 40-70 years from the Healthy Brain Project(HBP), were eligible and invited to participate. Individuals were categorized into three groups: 1) non-responders (did not respond to invitation; DBRR n=1878; HBP n=4677), 2) non-participants (not interested or screen failed; DBRR n=2322; HBP n=115) and 3) participants (randomised; DBRR n=1175; HBP n=407). Data was collected via the intake assessments of the online registries. Multinomial logistic regressions were used to determine associations between participation groups (participants as reference), and socio-demographic, medical and lifestyle factors. FINGER-NL non-participants were asked to provide reasons for declining the invitation through the DBRR portal. RESULTS: In FINGER-NL, compared to participants, non-responders were more often individuals with ≤12years of education, smokers, overweight, had diabetes, psychiatric or neurological conditions. Similarly, non-participants were also more likely to have ≤12years of education and were older. In BetterBrains, non-responders were more often individuals with ≤12years of education, younger, males, and had diabetes. Individuals with a family history of dementia, hypertension or high cholesterol are less likely to be non-responder. The most common reasons for non-participation mentioned in FINGER-NL were time-related constraints (39%, n/N=361/925), no interest (23%, n/N=209/925), and personal health (13%, n/N=123/925). CONCLUSION: Non-participants and non-responders for two multi-domain lifestyle RCTs recruited via online recruitment registries seem less healthy and have lower educational attainment, which has implications for the external validity. Focus-groups are currently underway to explore reasons underlying non-participation. Results can inform strategies to minimise non-participation in future trials.

Innovation in care and research - Dementia registries

P22. Dementia registries

P22-02Trends in dementia diagnoses and treatment in the elderly population of sweden: a 2015-2022 analysis

Bengt Winblad, Robin Zhou, Sofia Egebäck, Michael Axenhus
Karolinska Institute

Introduction: This study investigates age-standardized rates of dementia diagnoses and prescribition of dementia drugs in Sweden among individuals aged 65 and older from 2015 to 2022, focusing on three primary diagnoses—F00 (Alzheimer's disease), F01 (Vascular dementia), and F03 (Unspecified dementia). Dementia drug prescribition ATC-code was N06D. The primary objective is to analyze trends in diagnostics and treatment. Methods: Data sourced from national healthcare records includes age-standardized rates measured as dementia diagnoses and prescribition of dementia drugs per 100,000 inhabitants for individuals aged 65 and older. Gender-specific trends for F00, F01, and F03 are analyzed using descriptive statistics and Poisson regression. Results: For F00 dementia diagnoses, both males and females exhibit a consistent decline from 2015 to 2019, followed by a substantial reduction during 2020-2023. Males experience a decline from 7.4 to 6.6, while females have a notable drop from 7.3 to 3.9. Similarly, F01 vascular dementia diagnoses demonstrate a substantial decrease in both genders post-2019. Males witness a decline from 110.6 to 78.3, while females see a drop from 91.1 to 63.9. Dementia drug prescription increased during the study period from 8 632 to 13 643 with women being prescribed more dementia drugs then men. Conclusion: This study reveals a significant decline in dementia diagnoses, particularly Alzheimer's and vascular dementia, among individuals aged 65 and older in Sweden from 2015 to 2023. Additionally, there has been an increase in the prescription of dementia drugs over the same period, with women being prescribed more than men. These findings highlight potential shifts in diagnostic practices and treatment approaches in managing dementia in the Swedish population.

Innovation in care and research - Dementia registries

P22. Dementia registries

P22-03The international registry for Alzheimer's disease and other dementia (InRAD): a new database and collaboration platform

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Objectives: We present a new international and prospective, practice-based registry initiative for Alzheimer's disease (AD). This registry will collect real-world data on people with AD, including safety and effectiveness data for those treated with disease-modifying drugs. Methods: This is a collaborative, multi-stakeholder effort with contributions from the AD community. A minimum core dataset will ensure consistency and interoperability of data. An extended dataset will enable contributors to conduct a deeper analysis of practice and to participate in a range of real-world studies. InRAD will use an established technology platform, providing data ownership at site level and established governance for multi-centre studies with participant acknowledgement. Anonymized patient data will contribute to studies and secondary data analyses using established and advanced analytics including AI. Results: The main deliverables will be; a patient dataset with individual patient dashboards at each contributing centre, supporting clinical decision-making and local practice audit; and an anonymized, secure platform of aggregated real-world data that answers important questions for care of people with AD across the globe. Conclusions: The need for an international registry is underscored by the major global health issue that AD represents with emerging treatments and management tools. It will fill a crucial gap by connecting clinical communities in different countries through large-scale real-world studies. It will guide practice and future research, support regulatory and payer decisions, foster knowledge sharing, and accelerate progress in AD.

Innovation in care and research - Dementia registries

P22. Dementia registries

P22-04Validity of the short 10/66 dementia diagnostic schedule: preliminary findings in Portugal

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European epidemiological data regarding dementia is becoming outdated. One major cause is the cost and burden of classical fieldwork surveys. The 10/66 Dementia Research Group diagnostic algorithm is cross-culturally valid. It has been used in low and middle income countries and yielded prevalence data in Europe (1). Acknowledging its extension, a 'short 10/66' schedule was recently validated in Italy and Switzerland (2). We aimed to assess the 'short 10/66' validity in Portuguese samples, using mobile devices to facilitate data collection and including people with clinically established diagnoses to improve the robustness of our findings. The study was conducted on persons aged 60 years or older, in primary care, hospital outpatient clinics or psychogeriatric inpatient units. For each participant a trusted informant was also interviewed, a close relative for community-dwellers or a formal carer for institutionalised people. The 'short 10/66' was administered using REDcap (a browser-based, metadata-driven software) in mobile devices (a tablet or a smartphone). Recruitment and fieldwork were completed in April 2024 (n=240, of which 91 persons had a clinical diagnosis of dementia while those cognitively health were considered 'controls'). Quantitative analyses are ongoing to estimate the sensitivity and specificity of the 'short 10/66' dementia case definition. We expect this short schedule to be a practical tool that may prove helpful to identify dementia in these populations. We also hope that it may facilitate routine data collection in health/social services, potentially improving the feasibility and decreasing the costs of epidemiological surveys in Portugal as in other countries.References: Gonçalves-Pereira M, et al. The prevalence of dementia in a Portuguese community sample: a 10/66 Dementia Research Group study. BMC Geriatr. 2017;17(1):261, Ibnidris A, et al. Italian version of the short 10/66 dementia diagnostic schedule: a validation study. BMJ Open. 2021;11(6):e045867

Innovation in care and research - Dementia registries

P22. Dementia registries

P22-05Sex differences in the association of tau pathology, neurodegeneration, and cognition in a memory clinic setting

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This study investigated sex differences in the associations between Alzheimer's disease (AD) neuroimaging biomarkers and cognitive performance and decline in a memory clinic setting. 249 participants (females/males:123/126) were included from Geneva and Lausanne Memory Clinics. All underwent 18F-Flortaucipir-PET (171 with a dual-phase protocol), amyloid-PET, and T1-MRI. Mann-Whitney U tests investigated sex differences in clinical variables and AD biomarkers. Linear regression models estimated the moderating effect of sex on the relationship between biomarkers and cognitive performance and cognitive decline. Differences in cognitive decline were further assessed using longitudinal linear mixed-effect models with three-way interaction effects. Females and males did not differ in terms of clinical features, amyloid, and neurodegeneration (measured by MRI cortical thickness and tau-PET early-phase hypoperfusion). Females had a higher tau load than males ($p<0.001$). Tau associations with amyloid ($b=0.004, p<0.001$), neurodegeneration ($b=-0.10, p<0.001$) and MMSE ($b=-0.03, p<0.001$) were moderated by a significant interaction with sex. The association between amyloid and tau was stronger among women than men ($b=0.001, p=0.04$), whereas the associations between tau and MMSE and between tau and neurodegeneration were stronger among men than in women ($b=-5.37, p=0.001$ and $b=0.08, p=0.04$). Although all AD biomarkers correlated with cognitive decline ($p<0.01$), a significant sex moderation effect with a stronger association in women than men was found only with cortical thickness ($p<0.001$). Despite clinical comparability, females showed a higher tau load than males and a stronger association between amyloid and tau. In individuals with high tau burden, males exhibited greater neurodegeneration as measured as hypoperfusion and lower MMSE than females. However, in the presence of severe cortical thickness, females exhibited faster cognitive decline than males. These findings support the notion that sex differences may appear in the tau deposition, driven by different upstream interplay with amyloid, and leading to downstream effects on neurodegeneration and cognitive outcomes.

Policy - National Alzheimer's associations

P23. National Alzheimer's associations

P23-01An external evaluation of the Alzheimer Society of Ireland's 'Day Care at Home' service.

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University College Cork

Background: During the COVID-19 pandemic, the Alzheimer Society of Ireland set up a new domiciliary service, to replace traditional community-based day care services, as a much-needed outlet for social connection and meaningful activity. This service was labelled 'Day Care at Home' (DCAH) and comprised a model of social care delivered in people's own homes. Anecdotally, the client response to the service was positive, but further evidence was needed.
Aim: To conduct an external evaluation of the ASI's DCAH service across Ireland.
Methods: A qualitative research design was employed, with data collected through 1) semi-structured interviews with a range of 'key stakeholders', and 2) observations of the service in action via home visits. 'Key stakeholders' included people living with dementia, family carers, and ASI management and staff. Other stakeholders were external, e.g., primary care professionals, Health Service Executive senior managers and policy-/ decision-makers. Thematic analysis was conducted on the qualitative interview and observation data.
Results: A total of 37 in-depth interviews, and seven home visits were conducted across Ireland. Seven themes encompassing the findings of the evaluation (each with several sub-themes), were identified and are outlined in this section. These themes have been labelled as follows: 'A unique service model'; 'Dyadic Focus'; 'Person-centred care approach'; 'Referral pathways and access'; 'Service coordination'; 'Staff experiences'; 'Client outcomes'. While stakeholders identified potential areas for development, the service model and care approach had near universal support.
Conclusions: DCAH is a unique service, adding significant value to the dementia support landscape nationally. Stakeholders indicated that as well as improving the everyday lived experience and life quality of clients, DCAH service use can create a more sustainable family care situation. However, the demand is growing, stretching service capacity, and leading to lengthy waitlists and inequities in access. Increased funding is needed to sustain and democratise this service.

Policy - National Alzheimer's associations

P23. National Alzheimer's associations

P23-02A partnership with the National Union of Municipal and Intercommunal Social Action Centers (UNCCAS)

Lorène Gilly, Hélène Delmotte
France Alzheimer et maladies apparentées

In France, municipalities with more than 1,500 inhabitants are required to set up a Municipal Social Action Center (CCAS) which is chaired by the mayor or a deputy. Their missions consist of supporting and helping people in vulnerable situations: elderly people, people living with disabilities, precarious people. Many CCAS also manage nursing homes.
A National Union brings together these structures.
On April 16 2024, the president of France Alzheimer and the president of the National Union of Municipal and Intercommunal Social Action Centers (UNCCAS) signed an ambitious partnership agreement in order to better meet the needs of people living with dementia and their caregivers and run common approaches to improve policies' implementation on the field.
Actions will be deployed in different areas: support in administrative procedures, guidance in the healthcare system, information for the general public, training of health and medico-social professionals and municipal agents, etc.
"Unfortunately, Alzheimer's disease affects more and more people. This partnership with France Alzheimer is useful to the CCAS/CIAS of France, and will make it possible to better support people with dementia and their caregivers," expressed Luc Carvounas, president of UNCCAS.
This action is fundamental for the two partners who demonstrated their desire to act as close as possible to the families concerned, to encourage and then pool innovative support and to contribute, together, to the advent of a less discriminating and more inclusive society.
A monitoring committee was also set up to assess the progress of achievements and redirect certain actions if necessary.
For Joël Jaouen, president of France Alzheimer: "More and more communities are committing to being recognized as Alzheimer's caring cities or departments. This partnership with the National Union of CCAS/CIAS was essential for me for better local support for people living with dementia and their families."

Policy - National Alzheimer's associations

P23. National Alzheimer's associations

P23-03User involvement in Norway's dementia plan

Stine Hynne, Kari-Ann Baarlid, Anne Rita Øksengård, Marianne Naess
Norwegian Health Association

Background: The Norwegian Health Association is the national patient organization for persons with dementia and their carers.
Norway has been an early pioneer of developing dementia plans, currently on its third 5-year period. i The Ministry of Health and Care Services (HOD) has led this effort in close collaboration with us.
Aim: The primary aim was to achieve active and secure user involvement to atain the best possible outcome of the dementia plans, ensuring that the participants felt valued, respected, and supported. The overall goal was to demonstrate that people with dementia are crucial in developing such plans.
Method: We coordinated meetings between the Health Minister, HOD, our advisory boards, volunteers, and staff. Meetings with the experts by experiences '' Working group", the Dementia Council including researchers and caregivers, our peer support group, and meetings with advisors on our helpline, were organized by us.
Our role was to plan, facilitate, and conduct the meetings, as well as bringing forward the information we received to HOD. We emphasized on preparing and reassuring individuals with dementia and the caregivers that their experiences are valuable and cannot be obtained otherwise. It was crucial to ensure that the participants received sufficient and necessary information both beforehand and throughout the process. When smaller groups were advantageous, it was a safe space for thrust and sharing experiences.
Results and Impact: The Norwegian Health Association developed the chapter "Living with Dementia" in the Dementia Plan 2025, based on a comprehensive review of all received inputs. This was done in collaboration with people with dementia and other involved in the process.
This work has raised our organization's profile and reputation in user involvement, attracting interest from the health authorities and researchers for further collaboration.

Policy - National Alzheimer's associations

P23. National Alzheimer's associations

P23-04Integrated care for people with dementia in local communities with dementia friendly points

Štefanija L. Zlobec
Združenje Spominčica

Spominčica has implemented a 3-year Programme "Integrated dementia care in local communities", co-financed by the Ministry of Health. The main goal of the programme is to activate the local communities including service providers, local authorities and NGOs to connect the existing services for families living with dementia. With this programme we've connected organisations and institutions in local communities also with Dementia Friendly Points (DFP), which are coordinated by Spominčica. With this "upscaled" DFP network we aim to facilitate the inclusion of persons with dementia and their carers in local communities and stimulate their autonomy and cognitive functioning through active involvement in activities provided by local society.
Since 2017 more than 500 organizations have joined the DFP network: pharmacies, nursing homes, community health centers, centers for social work, chamber of health, museums, libraries, shops, banks, post offices, pharmacies, Ministries and others. Spominčica has developed a training programme for employees of organisations providing services to the general public, promoting solidarity. Member organizations provide friendly and accessible use of their services for persons with dementia and carers, share the information about dementia in the local community and promote the dementia friendly principles. Raising awareness about dementia has proven very positive for a chain of stores that has entered DFP network in 2022. Employees have improved their attitudes towards people with dementia and have a more human approach to their services.
With the Secondary School of Forestry and Woodworking we've developed tools and games to enhance cognitive function and motor skills in vulnerable groups, with a focus on helping people with dementia. Three farms were included as pilot environments. We've trained farm members on how to use the tools and support vulnerable groups in cognitive training. Our next steps include sharing knowledge with farms nationwide and raising dementia awareness in rural areas.

Policy - National Alzheimer's associations

P23. National Alzheimer's associations

P23-05Remember the path..Alzheimer Iceland

Sigurbjörg Hannesdóttir

The Alzheimer's Association was founded in 1985 and was called the original FAAS, an association of enthusiasts and relatives of Alzheimer's patients and other related diseases. In May 2016, its name was changed to the Alzheimer's Association.
The stated goal of the Alzheimer's Association is to protect the interests of its clients, promote cooperation and cohesion between relatives through educational meetings and publishing activities. Increase the understanding of the government, health professions and the public about the challenges that individuals with dementia and their relatives face from day to day.
We run a strong educational activity with regular educational meetings streamed online, education for institutions and companies and by maintaining a powerful website and social media. There is also a counseling and support service for both individuals and families.

Points about:

- Educational meeting
- Consulting services
- Psychological services
- Support groups
- Alzheimer's coffee
- Volunteer work
- Let's remember the path

The staff of the Alzheimer's Association has dedicated themselves to having positive, care, respect and progressiveness as a guiding principle in all their work. The values are a statement of how we work. Emphasis is placed on working on them in a targeted way. They are therefore a prerequisite for strengthening trust and promoting a long-term relationship between employees, health authorities, clients and their relatives.
Image of the values of the Alzheimer's Association: Positive – Care – Respect
The Alzheimer's Association runs two specialized day training programs Fríðuhús og Drafnarhús, as well as a Seiglan – service center for people mild cognitive symptoms and their relatives. Among other things, these resources aim to break the social isolation of individuals with dementia, maintain self-sufficiency and promote participation in daily activities.
All details are on our website www.alzheimer.is and social media: Alzheimersamtökin.

P24. Alzheimer Switzerland - Move your brain: Physical activity and dementia

P24. Move your brain: Physical activity and dementia

P24-02Combined physical and cognitive training to prevent cognitive decline

Arseny Sokolov
Centre Hospitalier Universitaire Vaudois

In the absence of causal treatment for cognitive decline due to neurodegeneration, cognitive training and neurorehabilitation are increasingly considered as promising options to maintain function and autonomy in people with beginning dementia. The combination of physical and cognitive exercise has been shown to bring about additional effects in both healthy elderly people as well as those with beginning cognitive decline. In particular, training integrating physical and cognitive tasks at the same time (dual-task training) has demonstrated promising outcomes, not only on cognition but also in reducing the risk of falls, for example. Such cognitive-physical dual-task approaches are increasingly implemented in video game environments, that are engaging and stimulating. The presentation will provide an overview of the scientific evidence for prevention of cognitive decline through cognitive-physical dual-task training, highlight trends in ongoing and future research, and provide some hands-on recommendations on how to implement dual-task exercise at home.

P24. Alzheimer Switzerland - Move your brain: Physical activity and dementia

P24. Move your brain: Physical activity and dementia

P24-03Exergame revolution for people with dementia

Eling D. de Bruin
OST - University of Applied Sciences of Eastern Switzerland

One way to introduce a cognitive element into a training program is using virtual reality techniques. There are reports on the use and effects of virtual reality exergaming training in different populations. Methods utilizing immersive computer technologies for example resulted in improved upper limb motor function and cortical activation following a virtual reality intervention in patients with chronic

stroke. Older adults benefited from training in terms of improved functional abilities, postural control and simple auditory reaction times under dual task conditions.

This presentation will focus on the relationship between the use of exergames and their impact on the physical and cognitive functions of older people with Alzheimer's disease. With increasing age comes a self-reinforcing downward spiral of reduced interaction with challenging environments and diminished brain health, which contributes significantly to cognitive decline. In addition, brain activity must be able to adapt to the challenges posed by the environment. Novel training paradigms, e.g. interaction with virtual reality and exergaming, could have an impact on brain function in the elderly. This talk will [1] discuss the theoretical relevance of novel exergame training approaches and [2] present research data suggesting that game-based physical and brain training focusing on aspects of neuromuscular function is effective in improving cognitive and physical function also in (frail) older people with Alzheimer's disease.

P24. Alzheimer Switzerland - Move your brain: Physical activity and dementia

P24. Move your brain: Physical activity and dementia

P24-04Panel discussion: implementing recommendations on physical activity

Margrit Leuthold
Synapsis Foundation - Dementia Research Switzerland

Regular physical activity over the whole life span is known as an important health factor, for the prevention of dementia and wellbeing of persons who are already affected. However, specific sports like soccer, ice hockey or football have downsides as head injuries are quite common, which are important risk factors to develop a dementia later in life.

In this inspiring session, three renowned experts, Nina Feddermann, BrainCare Mediacl GmbH, Zurich, Elin de Bruin, ETH Zurich, and Arseny Sokolov, CHUV, Lausanne, will give an overview of latest research findings of physical activity and sports on brain health over the life span. A panel discussion will follow, complemented with two additional

experts, Christina Zweifel, CURAVIVA, and N.N., who will give insights about successes and stumbling blocks of implementing such findings into daily life.

Patient pathways - Psychosocial interventions

P25. Psychosocial interventions

P25-01Reducing sleep problems in nursing home residents living with dementia - effectiveness of a tailored multicomponent psychosocial intervention (MoNoPol-Sleep-cRCT)

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Background: Sleep problems are common in people living with dementia, leading to health problems and reduced quality of life. Up to 23% of nursing home (NH) residents with dementia have sleep problems. No effective psychosocial interventions exist, there is some evidence that complex interventions with multiple components and a tailored approach have the best chance of being effective.
Objectives: Reduction sleep problems in people living with dementia using a multi-component psychosocial intervention in nursing homes.
Design and methods: Cluster-randomized controlled trial with two parallel groups and a follow-up of 16 weeks. Twenty-four NH were assigned to the intervention group (IG, 12 clusters, 126 participants) or the control group (CG, 12 clusters, 116 participants) using external concealed randomization. Participants are people living with dementia in nursing homes with at least two sleep problems. The intervention has six components: (1)

assessment of sleep-promoting activities and environmental factors (2) implementation and training of two "sleep nurses," per cluster (3) basic education, (4) advanced education for staff, (5) workshops to develop sleep-promoting concepts, and (6) written information and education materials. CG received standard care. The primary outcome was ≥ two sleep problems at 16 weeks assessed by the Sleep Disorders Inventory (SDI). Data entry and analysis was blinded.
Results: Twenty-two clusters (IG = 10, CG = 12) with 191 participants completed the study, the intervention was predominantly implemented as planned. At baseline, 90% of people with dementia in the IG and 93% in the CG had at least two sleep problems. After 16 weeks, the rates were 59.3% (IG) vs. 83.8% (CG), a difference of -24.5% (95% CI, -46.3% - -2.7%; cluster-adjusted odds ratio 0.281; 95% CI 0.087-0.909).
Conclusions: The MoNoPol-Sleep study demonstrated the effectivenes of a multicomponent psychosocial intervention for sleep problems in nursing home residents living with dementia without adverse effects.

Patient pathways - Psychosocial interventions

P25. Psychosocial interventions

P25-02 *The two faces of dementia:* Understanding the experience of grief and loss and developing support for people living with dementia

Claire Waddington
Rare Dementia Support

Background: Despite the prevalence of dementia, there is limited research on how people living with dementia navigate grief and loss following diagnosis. To address this gap and devise tailored interventions, we embarked on a qualitative metasynthesis of existing literature. We then directly engaged in research conversations on this topic with people living with dementia.
Methods: To conduct the qualitative review, we searched multiple databases including PubMed, PsycINFO, CINAHL, ASSIA, Web of Science, Scopus, Embase, and Emcare. Of the 1604 studies included in the initial search, 19 studies met inclusion criteria as determined by two independent reviewers. Following Long et al.'s (2020) guidance, we appraised and synthesized the included studies. High-quality papers formed the initial coding framework, supplemented by medium-quality papers, with low quality papers coded using the framework without adding additional codes. Inductive thematic analysis was used to synthesise these findings.

Findings: Included studies spanned nine countries (Australia (4), Canada (3), Finland (1), Israel (1), Japan (1), Norway (1), Sweden (3), the UK (3) and the USA (2)) with over 400 participants (N= ~25% living with dementia). Five key dimensions of grief in people living with dementia were identified: Grieving for the Person I Used to Be, Grieving for the Person I Will Become, Grieving for How Others See Me, Grieving for Those Who Have Died and What Helps Me With My Grief.
Conclusions: People living with dementia can experience grief related to a range of past, present and future losses. Given the deeply personal and individual nature of grief and loss, research that directly includes participants living with dementia is required. As such, we conducted research conversations with people living with dementia about their experience of grief and loss. We are currently in the process of analysing these findings and hope to share these results during the conference.

Patient pathways - Psychosocial interventions

P25. Psychosocial interventions

P25-03Social prescribing for people living with dementia: perspectives of service providers and link workers

Aimee Pick[1], Jane Cross[2], Work Package 1 Working Group Splendid[3], Louise Robinson[1], Emma Wolverson[4]
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Background: Social prescribing is an emerging approach in healthcare aiming to enhance health and well-being by connecting patients with non-medical services through link workers. Suggested as a means of ensuring access to holistic support for those with complex and varied needs, it offers the potential to help people living with dementia (PLWD) access non-pharmacological interventions within their communities. However, it is unknown how social prescribing link workers are supporting PLWD and if they believe it is a suitable service for them.
Methods: 22 semi-structured interviews were conducted via video call with regional leads of social prescribing services and social prescribing link workers to explore their experiences of working with PLWD and their perceptions on the suitability of social prescribing for PLWD. Regional leads and link workers had to be based in England, with link workers required to have experience or interest in working with PLWD. A snowballing sampling method was used and data analysed using thematic analysis.
Results: 3 themes were found: Supporting the Carer, Uncertainty of Working with

Dementia, and Role/Service Adaptability. Most link workers felt that you could not support PLWD without also supporting family carers, with some suggesting social prescribing was better suited to family carers than PLWD, or that PLWD could best be supported by working through the family carer. Uncertainty of how to interact with PLWD was expressed, with link worker dementia understanding and role/service adaptability being key factors in allowing social prescribing to fit the needs of PLWD.
Conclusions: The findings of this study suggest that while social prescribing is being accessed by PLWD the support they are gaining may be variable. If social prescribing is going to be increasingly suggested as the model of access to non-pharmacological support, then it needs to be further explored if this is the right approach for PLWD.

Patient pathways - Psychosocial interventions

P25. Psychosocial interventions

P25-04Person-centred practice in palliative aged and dementia care in Swiss long-term care facilities: a stepped-wedge cluster randomised trial

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Background: Current approaches to organising care in long-term care facilities (LTCFs) often overlook the insights of family members, despite their critical role in improving the quality of life and care of people with dementia. Incorporating family perspectives and using person-centred outcome measures, such as the Integrated Palliative Care Outcome Scale for People with Dementia (IPOS-Dem), can improve symptom recognition and person-centred outcomes by facilitating better communication between family members and frontline staff. However, there is a lack of effective and easy-to-use interventions for person-centred care of people with advanced dementia in LTCFs.
Method: A 15-month stepped-wedge cluster randomised design (N=240) was conducted in nine Swiss cantons to test the effectiveness of a person-centred care intervention for people

with dementia by advanced practice nurses in 23 LTCFs, based on IPOS-Dem. Three sequences were used for crossover from usual care to the monthly person-profiling intervention. The five-step person profiling intervention of describing, comparing, planning, implementing and evaluating involved frontline staff and family members and was repeated at least monthly.
Results: Quality of life, the primary outcome, was significantly improved ($p<0.001$, measured by QUALIDEM) with a person-profiling intervention. The five-step person-profiling intervention, delivered by advanced practice nurses, enables frontline staff and family members to fully assess and address the unique symptoms and concerns of the people they care for in a person-centred way.
Discussion: The nurse-led person-profiling intervention can directly improve dementia care and impact on people with dementia in LTCFs. People with advanced dementia living in Swiss LTCFs will experience improved quality of life and care as a result of the proposed intervention. The time required for the intervention is low, about 10 minutes per person. The Inter-RAI tariff system allows coding and reimbursement of this intervention.

Living with dementia - Empowerment and self-management

P26. Empowerment and self-management

P26-01Feasibility and acceptability of DELIGHT: a co-designed program to promote living well with dementia

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Improving supports to enhance wellbeing of people living with dementia is a priority of research and practice. The DEmentia Lifestyle Intervention Program for Getting Healthy Together (DELIGHT) was co-designed by people with dementia, care partners, health and social care providers, and researchers with the goal of promoting 'living well' with dementia among people living with dementia and care partners. This presentation will briefly review the co-design of DELIGHT and will share the evaluation of the feasibility and acceptability of the DELIGHT program over four pilot offerings (two virtual, two in-person). The DELIGHT program is an 8-week program that incorporates exercise and social, facilitated discussion on topics related to health and well-being (healthy eating, physical activity, social

support, mental well-being, sleep). Feasibility of DELIGHT was evaluated through recruitment, attendance, and completion rate, along with semi-structured interviews with participants and program instructors. Exploratory effectiveness outcomes included quality of life, physical activity, exercise self-efficacy, physical function, and nutrition risk. Twenty-two people living with dementia and 14 care partners were recruited to DELIGHT; 90% completed the virtual program and 100% completed the in-person program, with 78% and 90% attendance respectively. Exploratory assessment of effectiveness suggested improvements in quality of life, social connection, and physical activity. Thematic analysis of participant interviews indicated that DELIGHT was a warm and welcoming environment to gain the knowledge, confidence, and motivation to make positive changes in health behaviour. Participants described specific improvements in their daily function. Overall, DELIGHT provided hope and confidence for living well each day with dementia. These pilot results support the feasibility of DELIGHT and its potential as a strategy to support people living with dementia and family care partners to living well with dementia, though large-scale evaluation is needed.

Living with dementia - Empowerment and self-management

P26. Empowerment and self-management

P26-02Family carer education; learning about learning in a carers' academy

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The Carers' Academy is an educational intervention to equip family carers of people with dementia with the knowledge and skills they need for their unique caring situations. Within the UK, family care accounts for 44% of the cost of dementia care; investment in family dementia education is critical to sustaining care at home. Facilitating the learning of dementia family carers requires educational know-how and practice expertise. The learning approach used in the Carers' Academy draws upon trauma-informed approaches, person-centred care and the fundamentals of care. It is underpinned by UWS's signature Care Empathia approach. This approach creates the conditions to deepen understanding of

dementia and its impact on brain and bodily health, appreciate emotional aspects of care and caring to strengthen empathy and gain skills required for practical actions and safe care solutions. This study explored the learning experiences of expert health and social care professionals new to delivering this complex model of family dementia education.

Reflective questionnaire data on in-the-moment reflections about facilitation from nineteen facilitators were thematically analysed. Two focus groups to explore learning in-depth from facilitating the Carer Academy with thirteen participants were analysed using a framework approach. Six themes were identified: *Thinking about learning safely, Doing it, discussing it and feeling it, Developing collaborative insights, The emotional work of facilitation, Being responsive to caring situations, Leading, learning and working as a team.* Our findings acknowledge the dynamic participation of family carers in creating and supporting their own learning and the learning of others. Facilitating dementia family carer education requires clinical practice expertise and confidence in delivering dementia practice-based education. Furthermore, a theory-guided approach underpinned by an appropriate transformational learning pedagogy directly informs and shapes the approach to facilitation. Recommendations for future interprofessional preparation to support dementia education for family carers are made.

Living with dementia - Empowerment and self-management

P26. Empowerment and self-management

P26-03Development of a new outcome measure of resilience for people living with dementia: the Bangor dementia resilience scale

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Background: A systematic review and psychometric evaluation of existing resilience measurement scales used with people living with dementia and their carers revealed a lack of resilience measures designed specifically with and for people living with dementia. In response, we have developed a new outcome measure of resilience for people living with dementia, with involvement of people living with dementia throughout the process.
Methods: The work follows rigorous methodology for developing health measurement scales including developing a new conceptual framework of resilience for people living with dementia; using the conceptual framework to draft items and pilot test the face and content

validity with professionals, people living with dementia and their carers; and preliminary field-testing and psychometric evaluation (construct validity, internal consistency and convergent validity with other measures).
Results: Development of the conceptual model suggests resilience as a multi-level construct that may be achieved by drawing on resources including psychological strengths; practical approaches to adapting to life with dementia; continuing with hobbies, interests and activities; strong relationships with family and friends; peer support and education; participating in community activities; and support from healthcare professionals. A process of item generation, assessment and refinement provided 63 items. These were explored through interviews with people living with dementia, with detailed feedback leading to removal of items and resulting in a 37-item draft measure. Preliminary field-testing of the draft measure with 193 people living with dementia led to a final 19-item measure.
Conclusion: The Bangor Dementia Resilience Scale provides a new strengths-based measure that may be a valuable tool towards provision of good person-centred care and support for people living with dementia, as well as for measuring positive responses to services and interventions.

Living with dementia - Empowerment and self-management

P26. Empowerment and self-management

P26-04Adapting self-management support for persons living with dementia: lessons learned from the Partner in Balance program

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Self-management is a powerful approach for support, empowering people to play an active role in their care process. When delivered through eHealth platforms, it offers accessible ways for providing resources and support. The Partner in Balance (PiB) program exemplifies this for family caregivers of persons living with dementia. Through online access and personalized coaching, PiB has shown significant improvements in caregivers' self-efficacy, perceived control, and quality of life compared to usual care. An important observation in the implementation process of PiB is that persons living with dementia make

an explicit request to make the program suitable for them too. However, this poses a major challenge and paradox, since persons with cognitive impairment must adapt to a condition that actually impedes their ability to adapt. This requires careful adjustment of PiB resulting in a tailored support program taking cognitive impairments into account.
In our efforts to tailor such a program, we conducted two focus groups and planned two co-creation sessions involving individuals living with dementia. These sessions revealed promising insights into the potential benefits and personal needs of such support. However, they also highlighted challenges that are crucial to address in the delivery and format of support. For example, they highlight their growing inability to navigate computers, their reluctance to burden their partner with accessing support, but yet their desire to adapt to a new form of purpose, exploring coping strategies, and creating new routines aligned with their personal values. Our lessons learned in the transition from the PiB program into a version for individuals living with dementia will be shared and discussed. The availability of a PiB version for both persons with dementia and their caregivers offers the possibility of a dyadic approach, enabling mutual benefits as they support each other positively.

Living with dementia - Empowerment and self-management

P26. Empowerment and self-management

P26-05Finding the power within

Gerry Paley, Kathleen Farrell
The Alzheimer Society of Ireland

A diagnosis of dementia is life changing and very often it can destroy a person's confidence. So, it is therefore necessary to enable people to use their voice and empower them to continue to live a meaningful life.
How do we do that? We Build their capacity.
This presentation is a case study on the capacity building journey of Irish Dementia Working Group member Katheen Farrell.
The presentation will explore how building capacity for people living with dementia is essential to their well-being and society as a whole.
In less than two years Kathleen has progressed from being afraid to tell people in her community about her diagnosis to leading a national media campaign in Ireland. She has appeared in numerous national newspapers, taken part in several interviews, spoken at policy events and The Alzheimer Society of Irelands Pre Budget Submission.

The presentation will map Kathleen's journey from her first call to The Alzheimer Society of Irelands helpline in September 2022 to being on a billboard in the middle of the capital city. The presentation will highlight the highs and lows of this journey and share lessons learned and recommendations for future capacity building.

P27. INTERDEM An intersectional perspective on dementia care research: Understanding and reducing inequities

P27. An intersectional perspective on dementia care research: Understanding and reducing inequities

P27-02From a European Taskforce to a UK-funded network: bringing together diverse stakeholders to explore and identify solutions to dementia inequities

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People living with dementia often face significant barriers in accessing a diagnosis and care. So do their family carers. These barriers, which include ethnic or financial background, age (young-onset dementia), rarer dementia subtype, availability of carer, lack of health care professional knowledge and communication, lack of health and social care integration, and availability and suitability of services, can lead to inequitable outcomes for people living with dementia and their carers. Importantly, these barriers tend to intersect. Thus, exploring and addressing inequities in dementia diagnosis and care needs to take a comprehensive and wide view of these factors.

One way to increase our understanding of the landscape of inequalities across different European countries, and ideas for solutions to increase equity, are to bring together diverse stakeholders and share learnings across and within countries.

In 2022, the INTERDEM Taskforce on Inequalities was launched, which to date has 13 European countries represented and works collaboratively with Alzheimer Europe. The Taskforce has so far completed one survey and consultation exercise across 10 European countries (published), one systematic review on misdiagnosis (under review), and one systematic review on solutions to inequalities in dementia diagnosis and care (ongoing).

Learnings from this European Taskforce have fed into a newly funded 5-year UK network on solutions to inequalities in dementia diagnosis and care - EquaDem Network Plus. EquaDem Network Plus comprises of 7 Universities, two Charities, social care organisations, and an NHS Trust at its core. The aim of the network is facilitate strong networks among different stakeholders in dementia across the country, and pump prime ideas or developments of solutions to inequalities, and build capacity in the health and social care workforce and early and mid-career researchers.

This talk will showcase the value of cross-country and cross-stakeholder collaboration, and opportunities for involvement in the UK and Europe.

Living with dementia - Relationships and sexuality

P27. An intersectional perspective on dementia care research: Understanding and reducing inequities

P27-03Sexuality and intimacy in dementia care: systematic review and intersectional analysis of guidelines

Hannah Christie[1], Isabeau Van Rompuy[1], Marjolein de Vugt[1], John Gerard Dinsmore[2], Anne-Marie Brady[2]
[1]Maastricht University, [2]Trinity College Dublin

Background: Sexuality and intimacy are fundamental to quality of life in people with dementia and should be addressed as part of holistic dementia care guidelines.
Objectives: (1.) Provide an overview of guidelines in the scientific literature on sexuality and intimacy in dementia care; (2.) Conduct an intersectional analysis to identify how diverse needs are addressed in these guidelines.
Methods: Included sources are guidelines that (1.) focus on improving dementia care for the entire dementia care triad (care professionals, informal carers, and people with dementia), and; (2.) meaningfully discuss sexuality and intimacy. The search was carried out in PubMed, CINAHL, Embase, PsycINFO, and Cochrane Library, in April 2024. Two

independent reviewers screened the titles and abstracts of the identified references, and then the full texts. The Intersectionality-Based Policy Analysis (IBPA) framework was applied to identify areas where the diverse needs of the dementia care triad have been addressed.
Results: Eleven references were included. Ten guidelines targeted care professionals, while one guideline targeted care professionals and couples in early stages of dementia. Most guidelines focused on general policy recommendations concerning sexuality and intimacy in long-term dementia care. Two guidelines included recommendations for education and community, and two guidelines focused on consent and abuse in dementia. While the majority of the guidelines discussed sexual orientation, gender, or age (one guideline mentioned religion), there was a lack of attention to how these factors can intersect and create unique challenges in practice and policy.
Conclusions: Available guidelines on sexuality and intimacy in dementia care, in the scientific literature, are largely targeted at care professionals in long-term care. Future research should take an intersectional approach to create guidelines that target the diverse needs of the entire dementia care triad and assess guidelines in the grey literature.

P27. INTERDEM An intersectional perspective on dementia care research: Understanding and reducing inequities

P27. An intersectional perspective on dementia care research: Understanding and reducing inequities

P27-04Exploring Dementia Service Access and Avoidance by older LGBTQIA+ Adults

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Objectives: The aim of the study was to gain an understanding of the experiences of LGBTQIA+ people with dementia and their caregivers, and whether dementia services are accessed or avoided by this population for any reason relating to their sexuality or gender identity.

Method: Six semi-structured interviews were conducted, three with professional dementia-service providers, and three with LGBTQIA+ service users based in the Republic of Ireland. Thematic analysis (Braun & Clarke, 2006), was used to analyse the data.

Findings: Five themes were identified including, 'Individual differences and LGBTQIA+ needs', 'Saliency, service use and avoidance', 'Feeling out of place', 'Listening to LGBTQIA+ people as experts' and 'Explicit communication of acceptance'.

Conclusion: The saliency of dementia-symptoms can encourage service use, but socioeconomic problems more prevalent than symptoms can discourage service use. Heteronormativity in dementia social-groups can also reduce service use, thus creating LGBTQIA+ socialising-services may be advantageous. If non-LGBTQIA+-specific dementia services publicly advertised that their service is LGBTQIA+-friendly, anxiety of people with dementia and their caregivers may reduce. Mandatory staff training in LGBTQIA+ care may help LGBTQIA+ people feel more included and safe.

P27. INTERDEM An intersectional perspective on dementia care research: Understanding and reducing inequities

P27. An intersectional perspective on dementia care research: Understanding and reducing inequities

P27-05Inequality in the quality and safety of post diagnostic primary care for people with dementia: emerging results of a systematic scoping review

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Introduction: There is guidance for providing safe, high-quality post-diagnostic primary healthcare for people with dementia. Evidence suggests the quality and safety of this healthcare varies with socio-economic status (SES).
Objective: This scoping review aimed to understand existing evidence exploring socio-economic variation in the quality and safety of primary care for people with dementia.
Methods: Prescribing and care planning indicators of high-quality, safe primary care were defined from existing international guidance. Composite and proxy markers of SES were defined. EMBASE, MEDLINE, PsychInfo, the Cochrane Database of Systematic Reviews, worldcat.org and clinicaltrial.gov databases were searched. Studies in English, on human

subjects from 2006 onwards were eligible. Abstracts were screened by 1 reviewer; a second reviewer screened 10% of full texts.
Inclusion criteria: Studies must have explored how one or more of: anti-dementia medication prescribing, anti-psychotic prescribing, potentially inappropriate prescribing (PIP), medication review, dementia review or care planning, varied with a recognised proxy or composite marker of SES in people with dementia.
Emerging Results: Searches identified 1921 studies after removing duplicates. 384 full texts were reviewed, with 53 eligible for inclusion (51 quantitative, 2 reviews). The majority of identified studies explored prescribing indicators (50 quantitative, 2 reviews), with 2 exploring annual reviews. Heterogeneity in SES markers precluded meta-analysis; narrative synthesis was conducted.
There was evidence of substantial disparity in quality and safety indicators in included studies exploring prescribing; 20/28(70%) of studies exploring anti-dementia medication prescribing found those with markers of lower SES were significantly less likely to receive these. 16/25 (64%) studies exploring PIP/Anti-psychotics found significant disparities in safe prescribing for those with lower SES. Neither study exploring annual reviews found significant differences.
Conclusion: The scoping review found evidence of disparity in the quality and safety of post-diagnostic primary care for people living with dementia based on socio-economic status, particularly for prescribing indicators.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P28. Intellectual disability and Down syndrome II

P28-01Stand by Me: experiences of couples with intellectual disability when one partner has dementia

Karen Watchman, Karen Watchman
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People with intellectual disabilities are at increased risk of dementia at an earlier age. At the same time, individuals are living longer and enjoying greater quality of life, including relationships and marriage. Stand by Me is the first study to explore the experiences of couples with intellectual disabilities when one partner has a diagnosis of dementia. The need for the study was identified by a married man with an intellectual disability and dementia who remained an integral part of the UK research team.

Life story interviews were conducted with five people with intellectual disability whose relationship was, or had been, affected by dementia. Other participants were nine social care professionals and four family members with experience of supporting the couples, or one of the partners. When combined, this produced data from eight couples that was thematically analysed. Three adults with a learning disability joined the research advisory group.
The eight couples had been together for a combined total of 170 years; the longest relationship had lasted 20+ years. Couples identified a need for information about dementia and expressed fears for the future. Families reported that their expectations and assumptions continued to be challenged through the course of the relationships whilst intellectual disability support staff did not always include the couple in decision making. Support included recognition of the role of the partner without dementia as primary carer, availability of counselling, access to palliative care, understanding previous life experiences of both partners and multi-disciplinary learning disability and dementia training.
Stand by Me demonstrated that couples with intellectual disability can continue to enjoy loving and intimate relationships after one of the partners receives a diagnosis of dementia. However, additional and unique challenges were faced that were different to couples affected by dementia who did not have an intellectual disability.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P28. Intellectual disability and Down syndrome II

P28-02Dementia in people with intellectual disabilities: from relevance of a diagnosis to two new instruments aiding the diagnostic process

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With increasing life expectancy, dementia has become more prevalent among people with intellectual disabilities, particularly those with Down syndrome (DS) who face a high genetic risk of Alzheimer's disease. Diagnosing dementia in this population presents unique challenges due to pre-existing disabilities, comorbidities and behavioural patterns. The more severe the disability, the more complex it is to diagnose dementia.
Behavioural and Psychological Symptoms of Dementia (BPSD) are of particular interest in this context, often serving as early indicators of dementia. When cognitive decline is harder to note, behavioural changes are often better observable. However, evaluating BPSD in people with DS requires specialized approaches and cannot rely on behavioural instruments

used in the general population. Therefore, to address this need, we developed the BPSD-DS 2 scale (52 items) that comprehensively assesses BPSD by disentangling behavioural changes from lifelong characteristic behaviour. Validation of this scale involved 524 individuals with DS divided into three groups no dementia (DS, N=292), questionable dementia (DS+Q, N=119), and clinically diagnosed dementia (DS+AD, N=113). Comparing groups, prominent changes were found in, among others, anxious and apathetic symptoms, with the proportion of individuals showing an increased frequency being highest in DS+AD and lowest in DS.
For people with severe/profound intellectual disabilities, including approximately 20-30% of people with DS, an even more targeted approach is needed. Existing assessment tools often fall short in capturing dementia-related changes. Therefore, we developed a diagnostic aid for psychologists to identify such changes. In a first pilot study, this diagnostic aid with 42 items, including 15 items about BPSD, showed promising results. Behavioural scores were significantly higher in the group with dementia versus the group without.
This presentation highlights recent insights about the relevance of a dementia diagnosis among people with intellectual disabilities and the use of two new instruments designed to facilitate the diagnostic process.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P28. Intellectual disability and Down syndrome II

P28-03Alliade screening down syndrome (ASDS): a periodic screening for early detection and diagnosis of age-related symptoms in people with down syndrome.

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Individuals with Down syndrome (DS) experience accelerated ageing and an elevated risk of early-onset dementia. Diagnosing dementia in this group presents challenges due to age-related conditions and comorbidities. Moreover, baseline assessments that facilitate timely detection are often lacking, creating a gap in healthcare provision. Timely diagnosing of dementia is crucial for appropriate care and treatment. This encompasses value-driven and

outcome-oriented care, ensuring appropriate care placement.
In response to these challenges, Alliade, a healthcare organization based in the Dutch province of Friesland, has introduced the Alliade Screening Down Syndrome (ASDS). This comprehensive screening program is tailored to individuals with DS, aiming to promptly identify indications of decline and dementia, thereby enabling personalised care adapted to individual needs.
Within the ASDS, we adhere to (inter)national recommendations and guidelines, utilizing validated instruments specifically designed for individuals with DS. Periodically, the screening program is refined based on new scientific insights and current innovations. Moreover, the ASDS offers the option to provide consent for the use of collected data for scientific purposes, aiming to gain a better understanding of aging and dementia in people with DS. This dual-purpose approach not only ensures screening according to the latest developments but also contributes to further substantiation, validation, and research in this field.
This presentation highlights the principles of the ASDS and shows the very first cross-sectional results including 100 people (age 29-66 years) with DS with and without dementia. The overall prevalence of (questionable) dementia was 21,8% and being associated with age-related conditions such as sleep apnea, hearing and visual impairments.
This screening program results in a more user-friendly, efficient, and cost-effective process. Early detection facilitates prompt adjustments to appropriate care and personalized support (e.g. psychosocial support methods). This promotes a more systematic approach in addressing the complex needs of ageing individuals with DS.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P28. Intellectual disability and Down syndrome II

P28-04From suspicion to diagnosis: the procedure for suspected dementia in people with intellectual disabilities in austrian facilities for people with disabilities

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People with intellectual disabilities, particularly those with Down syndrome, are not only at increased risk for dementia, but are also affected by an early onset (Alzheimer's

Association, 2022; Iulita et al., 2022). Early diagnosis of dementia is therefore essential to provide adequate health care and to maintain the quality of life (Zeilinger et al., 2022). However, early detection of dementia is particularly difficult in this population, especially in Austria, where the topic of dementia and intellectual disability is relatively new (Denninger, 2020). Consequently, there is a shortage of clinical experts in this field and a lack of standardised diagnostic procedures (Schachner et al., 2022). Therefore, the objective of this research is to investigate the process that professional carers follow when a suspicion of dementia in people with intellectual disabilities arises. To this end, the following research questions will be addressed:

- How do professional carers deal with suspected dementia in people with intellectual disabilities?
- How are informal carers involved when dementia is suspected?
- What diagnostic procedures are initiated when a suspicion of dementia arises?

A total of 30 semi-structured face-to-face interviews were conducted with professional carers (25 women) between August 2021 and March 2022. The interviews were transcribed verbatim and analysed using "content-structuring qualitative content analysis" according to Kuckartz (2018).
Results showed, that professional carers first discuss their suspicions of dementia with colleagues and later went to their managers. Conversations with relatives are held if the suspicion has already been discussed in the team and with the management. Only eight respondents stated that their care recipients had been diagnosed with dementia by a medical professional. Additionally, carers highlighted the diagnostic difficulties associated with standardised tests and state that there are no referral services for making a diagnosis.

Inclusion and intersectionality - Intellectual disability and Down syndrome

P28. Intellectual disability and Down syndrome II

P28-05Development and preliminary psychometric properties of the first instrument to assess Cognitive Reserve for people with intellectual disability (CRI-ID)

Annalisa La Face[1], Dominik Pendl[1], Veronica Pucci[2], Barbara Gasteiger Klicpera[1]
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Background: In addition to the extensive research on dementia risk in people with intellectual disabilities, more research is needed on protective factors. Indeed, there is a high degree of inter-individual variability in disease resilience and resistance within this population (Allen et al., 2023), which may be explained through the concept of 'cognitive reserve' (CR). According to this theory, cognitively stimulating activities undertaken throughout life can delay the onset of dementia symptoms and modify disease progression. CR is therefore a variable worth assessing in the clinical evaluation of people with intellectual disabilities. However, existing instruments are not appropriate for this population because they do not include potential proxies that are specifically relevant to people with intellectual disabilities, as identified in a recent scoping review (Pucci et al., 2024).
Method: We developed the first questionnaire to assess CR in people with intellectual disabilities (CRI-ID) by operationalising the relevant proxies for cognitive reserve found in the literature (e.g., type of schooling; Pucci et al., 2024). We assessed feasibility through focus group interviews with formal and informal caregivers (N=6), refined the wording and layout of the questionnaire and administered it twice to 15 informal and 15 formal caregivers in two modalities (self-administered and administered) 2-4 weeks apart.
Results: The final questionnaire is divided into 7 sections: Social Network, Housing, Cognitive Stimulation, Education, Work, Sport, Leisure. We will present the structure of the questionnaire, the distribution of global and subscale scores, the test-retest reliability calculated through Pearson´s r, and the invariance across different assessment modes (two one-sided t-tests). In addition, the differences in response rates between formal and informal caregivers will be presented as a potential measure of reliability.
Conclusions: The CRI-ID will be useful for clinicians, but also for research to identify lifestyle factors that increase resilience to dementia in people with intellectual disabilities.

P29. Terumo Blood and cell technologies

P29. Innovative approaches in Alzheimer's disease: real-world safety and efficacy of therapeutic plasma exchange with albumin replacement

P29-01Feasibility of Therapeutic Plasma Exchange (TPE) with Albumin replacement in treating elderly patients with Alzheimer's disease: the AMBAR study

Yahveth Cantero-Fortiz[1], Mercè Boada[2], Federico Casales[2], Jordi Klamburg[2], Genis Carrasco[2], Xavier Sarmiento[2], Oscar Bascuñana[2], Judit Castro[2], Marta Parella[2], Nathalia Muñoz[2], Sergi Valero[2], Adela Orellana[2], Maitee Rosende-Roca[2], Antonio Paez[2], Miren Jone Gurruchaga[2], Lluis Tárraga[2]

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Background: Alzheimer Disease (AD) Management by Albumin Replacement (AMBAR) study assessed the feasibility, safety, and tolerability of two plasma exchange (PE) modalities with albumin replacement in elderly patients with mild-to-moderate AD.

Patients and Methods: This prospective, randomized, controlled trial was conducted at 41 sites in Spain and the United States. Patients with mild-to-moderate AD were randomized into four groups: placebo (sham PE), low-albumin (20 g), low-albumin + IVIG (10 g), and high-albumin (40 g) + IVIG (20 g). The study involved 6 weeks of weekly TPE followed by 12 months of monthly LVPE. Feasibility was assessed by completion rates of PE procedures, time required per procedure, and practicality of central versus peripheral venous access.

Results: A total of 322 patients participated in the study, with 4709 PE procedures performed (3486 real and 1223 sham). Completion rates were 79.7% in the placebo and 79.5% in the low-albumin groups, but lower in the IVIG groups (64.0% and 67.1%). TPE procedures initially took 110 minutes, decreasing to 96-108 minutes by the final sessions. LVPE procedures removed 690-880 mL of plasma, replaced with 100-200 mL of 20% albumin. Regarding safety, 10.6% of procedures had AEs within 72 hours, with higher incidence in TPE (16.9%) compared to LVPE (12.5%). Common AEs included catheter reactions, dizziness, and hypotension. Active treatment groups had higher overall AEs (90.1%) than the placebo (70.9%). Central venous access had more AEs than peripheral (20.1% vs. 13.1%). Despite these, 90% of procedures were uneventful, with no severe AEs, indicating TPE is generally safe.

Conclusion: The AMBAR study demonstrated that TPE and LVPE with albumin replacement are feasible, practical, and safe for treating elderly Alzheimer's patients. The procedures were manageable, with peripheral venous access recommended to minimize adverse events. These findings support the broader implementation of TPE and LVPE in clinical practice.

P29. Terumo Blood and cell technologies

P29. Innovative approaches in Alzheimer's disease: real-world safety and efficacy of therapeutic plasma exchange with albumin replacement

P29-02Efficacy of plasma exchange with albumin replacement in Alzheimer's disease: a prospective cohort study in a single center

Yahveth Cantero-Fortiz[1], Federico Casales[2], Jordi Klamburg[2], Genis Carrasco[2], Xavier Sarmiento[2], Oscar Bascuñana[2], Judit Castro[2], Marta Parella[2], Nathalia Muñoz[2], Fernando García-Gónzalez[2], Adela Orellana[2], Maitee Rosende-Roca[2], Antonio Paez[3], Miren Jone Gurruchaga[2], Lluís Tarraga[2], Mercè Boada[2]
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Background: Research suggests dynamic balance of amyloid-β (Aβ) peptide between cerebrospinal fluid (CSF) and plasma compartments. Therapeutic plasma exchange (TPE) reduces peripheral Aβ, potentially altering this balance and lowering CNS amyloid levels. TPE has shown efficacy alleviating symptoms and slowing Alzheimer's disease. This study aims to validate prior findings on the cognitive benefits of TPE with albumin replacement in mild to moderate syndromic Alzheimer's Disease (AD) within real-world conditions.

Patients and Methods: This observational study included all consecutive patients with AD treated in our center from June 2021 to February 2024. Treatment consisted in six biweekly TPE intensive periods, followed by at least 12 monthly TPE. Apheresis procedures were performed using Optia (Terumo®) continuous flow centrifugation cell separator with albumin replacement (Albutein Grifols®). Neurological, neuropsychological, and functional perception assessments were conducted at baseline, three months, nine months, and fifteen months for all patients.

Results: 122 patients met the inclusion criteria and initiated TPE treatment. By the study's end, 97 (79.5%) completed 6 TPE, 68 (55.7%) completed 12 TPE, and 45 (36.8%) completed 18 TPE and underwent evaluation. Seventy-five participants were women (61%) with a mean age of 72.4±6.7. Mean MMSE score was 20.1±4.7, and participants had an average of 11 years of education. **Cognitive Outcomes:** While primary endpoints such as MMSE, Clock test, and BNT test showed a statistically significant mild decrement ($p < 0.05$), cognitive composite (NBACE) indicated stability and improvement during treatment. Patient-related outcomes (PROs) showed stabilization or improvement in 84.4% of patients based on the IGI scale, with similar perceptions reported by caregivers (77.97%).

Conclusion: These findings suggest that TPE with albumin replacement is efficient in mild to moderate syndromic AD patients and may offer cognitive stabilization benefits. Further research with larger populations is warranted to elucidate the role of TPE in the evolving landscape of AD treatments.

P29. Terumo Blood and cell technologies

P29. Innovative approaches in Alzheimer's disease: real-world safety and efficacy of therapeutic plasma exchange with albumin replacement

P29-03Safety of plasma exchange with albumin replacement in Alzheimer's disease: a prospective cohort study in a single center

Yahveth Cantero-Fortiz[1], Federico Agustín Casales[2], Jordi Klamburg[2], Genis Carrasco[2], Xavier Sarmiento[2], Oscar Bascuñana[2], Judit Castro[2], Marta Parella[2], Nathalia Muñoz[2], Fernando García-Gónzalez[2], Adela Orellana[2], Maitee Rosende-Roca[2], Antonio Paez[2], Miren Jone Gurruchaga[2], Lluís Tarraga[2], Mercè Boada[2]
[1]Ace Alzheimer Center Barcelona-Institut Catalá de Neurociencies Aplicades, [2]Ace Alzheimer Center Barcelona; Barcelona, Spain.

Background: Research indicates dynamic balance of β-amyloid peptide (Aβ) between cerebrospinal fluid (CSF) and plasma compartments. Therapeutic plasma exchange (TPE) may influence in this balance, reducing amyloid levels in CNS, potentially benefiting Alzheimer's disease (AD) patients, as seen in AMBAR study. This study aims to assess safety of TPE with albumin replacement in mild-moderate syndromic AD in real-world settings.

Methods: This observational study included all consecutive patients with AD treated in our center from June 2021 to February 2024. Patient eligibility was determined through initial visits where inclusion and exclusion criteria were confirmed. Multidisciplinary clinical assessments were conducted as baseline evaluations and comprehensive laboratory. Apheresis procedures were performed using the Optia (Terumo®) continuous flow centrifugation cell separator, ensuring continuous plasma exchange. Treatment consisted of six biweekly TPE with albumin replacement (Albutein Grifols®) intensive periods, followed by 12 monthly TPE maintenance. Continuous monitoring and direct supervision by specialists ensured procedural

safety. Regular clinical interviews were conducted, with family involvement and post-treatment follow-ups for adverse effects assessment.

Results: 122 patients met inclusion criteria and initiated TPE treatment. Ninety-seven persons (79.5%) completed 6 TPE, 68 (55.7%) completed 12 TPE, and 45 (36.8%) completed 18 TPE and underwent evaluation. Seventy-five participants were women (61%) with a mean age of 72.4±6.7. Mean MMSE score was 20.1±4.7, and participants had an average of 11 years of education. Safety Endpoints: Out of 2,129 TPE procedures performed, 97.6% were uneventful, with only 2.3% experiencing mild adverse events, including hypotension (1.3%), discomfort (0.1%), syncope (0.3%), paraesthesia (0.0%), and other minor issues (0.3%). Phlebitis and serious adverse events were not reported.

Conclusion: These findings suggest that TPE with albumin replacement is safe in mild to moderate syndromic AD patients. Further research with larger populations is warranted to elucidate the role of TPE in the evolving landscape of AD treatments.

Innovation in care and research - Preparing for new AD treatments

P30. Preparing for new AD treatments

P30-01Anti-amyloid therapies for Alzheimer's disease: an Alzheimer Europe position statement and call to action

Angela Bradshaw[1], Jean Georges[2]
[1]Alzheimer Europe, [2]

The growing prevalence and burden of Alzheimer’s disease has catalysed huge investments in research on its causes, diagnosis, treatment and care. After many high-profile failures, recent clinical trials of anti-amyloid drugs have marked a turning point for the field, leading to the approval of the first disease-modifying therapies for Alzheimer’s disease by the FDA. At the time of writing, European regulators are determining whether there is sufficient evidence to approve these drugs for patients with mild cognitive impairment or mild dementia due to Alzheimer’s disease. In this presentation, we will outline the Alzheimer Europe (AE) position on anti-amyloid therapies for Alzheimer’s disease. We will also show how the position was developed in consultation with national Alzheimer's associations across Europe, as well as members of the European Working Group of People with

Dementia (EWGPWD). The AE position paper addresses questions of anti-amyloid drug efficacy, safety and cost, highlighting three priority areas to ensure equitable access to these innovative treatments: Clear and accurate communications on the benefits and risks of anti-amyloid drugs, allowing people with AD and their carers to make informed choices about treatment, Equitable access to a timely and accurate AD diagnosis for all, regardless of ethnicity, socio-economic status, language or geographical location, Concrete actions and investments in European healthcare systems to prepare for a future where anti-amyloid drugs should be readily accessible for everyone who could benefit from treatment. Reflecting on recent outcomes of regulatory processes, we will present the AE call to action on anti-amyloid therapies, which identifies concrete actions from industry, payers, healthcare systems and governments to to ensure that patients have timely, appropriate and equitable access to these innovative treatments, regardless of their socio-economic background, insurance status, or place of residence.

Innovation in care and research - Preparing for new AD treatments

P30. Preparing for new AD treatments

P30-02New drugs in AD: profiling italian centers for cognitive disorders and dementias

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Background: The Italian Fund for Alzheimer's and other dementias approved in 2020 enabled the conducting of a survey in Italian Centers for Cognitive Disorders and Dementias (CCDDs) to analyze the organization , the administrative features and the professional competencies. Moreover the advent of disease-modifying therapies (DMTs) for Alzheimer's Disease will require the presence of facilities with specific characteristics to meet the drug's prescription criteria. Objective: The aim is to suggest a profile of the Italian CCDDs that could be taken into consideration by regional and autonomous provincial authorities when

deciding on the prescribing centres for DMT. Additionally the study aims to compare facilities with prescriptive capabilities with others, highlighting differences in organizational aspects and activity profiles, services provided to the patients, and continuing professional development and counseling service. Methods: A national survey was conducted using an online questionnaire between July 2022 and February 2023. Based on responses to questionnaire on CCDDs in Italy (450 facilities), we identified the CCDDs that meet the requirements for effective prescription: i) Multidisciplinary team; ii) Minimum Core Test for the neuropsychological assessment; iii) PET, CSF, and Brain MRI assessments. Univariate and multivariate comparisons were conducted between CCDDs that met the criteria and the others. Results: Only 10.4% of CCDDs met the requirements for effective DMT prescription, with significant differences in geographical distribution. These CCDDs were also associated with other structural and organizational characteristics such as opening hours, number of professionals, and location. Conclusion: The findings suggest that the Italian national healthcare system may benefit from further enhancements to facilitate the effective prescription of DMTs. This could involve initiatives to reduce fragmentation, ensure adequate resources and equipment, and secure sufficient funding to support CCDDs.Project carried out with the technical and financial support of the Ministry of Health chapter-2302.

Innovation in care and research - Preparing for new AD treatments

P30. Preparing for new AD treatments

P30-03Clinician-patient communication about the new disease-modifying treatment(s) for Alzheimer's disease: the perspective of memory clinic patients and care partners

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Background: The first disease-modifying treatments (DMTs) for Alzheimer's disease(AD) have been approved in a few countries around the world, marking profound changes in AD-diagnosis and treatment. This brings new challenges in clinician-patient communication. We aimed to gather the perspectives of memory clinic patients and their care partners on their information needs and what would support a meaningful conversation about whether or not

to initiate DMT.
Method: We conducted semi-structured interviews with eleven patients with AD (mostly mild cognitive impairment, age 58-75y, 54.5% female) and fourteen care partners, often a spouse (age 22-81y, 42.8% female). All interviews started with a brief explanation about DMTs. Then, we presented a hypothetical scenario in which DMTs were approved in Europe and asked questions such as: “What questions would you have?” and “What could help when talking about DMT?”. We analyzed the transcribed audio-recordings using thematic analysis.
Results: A first theme concerned the varying levels of curiosity and knowledge about DMTs among participants. Second, participants wanted to know about the pros and cons of DMT, especially the side-effects and how their daily lives would be affected during and after treatment. Third, they wanted to make the decision about initiating DMT together with their clinician, but they differed in their control preference; some preferred complete control, while others wanted their clinician to make the final decision. Fourth, participants expressed a need for independent and accessible tools to help them prepare for clinician-patient consultations.
Conclusion: Prior knowledge, information needs, and decision control preferences regarding DMT for AD vary from person to person, highlighting the value of person-centered communication. To enable all patients and care partners to weigh the pros and cons of DMT, they must be well-informed and supported in the process of shared decision-making. For example, by means of educational and/or communication tools, developed in co-creation.

Innovation in care and research - Preparing for new AD treatments

P30. Preparing for new AD treatments

P30-04Binding characteristics of PRX012 surrogate demonstrate potent engagement of toxic amyloid beta protofibrils and robust clearance of pyroglutamate-modified amyloid beta

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Objective: To build a more detailed understanding of the biological activity and binding interactions of PRX012, a next-generation, subcutaneously delivered anti-amyloid-beta (Aβ) monoclonal antibody (mAb) under investigation for the treatment of Alzheimer's disease (AD). Background: Multiple clinical trials evaluating first-generation anti-Aβ mAbs (aducanumab, lecanemab, donanemab) show that Aβ plaque reduction is associated with slowing clinical decline in AD. In addition to plaque reduction, two additional mechanisms of action, neutralization of toxic Aβ protofibrils (lecanemab) and clearance of pyroglutamate-modified Aβ in plaques (donanemab), have been described. PRX012 was designed as a subcutaneous IgG1 mAb to induce robust neutralization and clearance of aggregated forms of Aβ, including protofibrils and plaques, with relatively low doses/volumes due to its high binding avidity. Here, we describe nonclinical evaluations that compared head-to-head 1) the binding of a PRX012 surrogate (PRX012s) and lecanemab to Aβ protofibrils and 2) the ability of PRX012s and donanemab to induce microglial clearance of pyroglutamate-Aβ from AD brain tissue. Design/Methods: Antibody binding to Aβ protofibrils was characterized by surface plasmon resonance using published methods for lecanemab. Antibody-dependent phagocytosis of pyroglutamate-modified Aβ from AD plaques was evaluated ex vivo with post-mortem AD brain tissue in the presence of microglia and potentially clinically relevant antibody concentrations. Results: PRX012s bound to Aβ protofibrils with nearly 20-fold higher affinity/avidity when compared with lecanemab. Binding kinetics for lecanemab were consistent with previously published values. PRX012s was substantially more potent than donanemab in promoting clearance of pyroglutamate-Aβ from plaques of AD tissue ex vivo. Conclusions: PRX012s, an N-terminal-targeted anti-Aβ mAb, demonstrated superior binding to protofibrils and phagocytic clearance of pyroglutamate-modified Aβ when compared with lecanemab and donanemab, respectively. These data further support the ongoing clinical development of PRX012 as a potential best-in-class anti-Aβ immunotherapy that could enable a low-volume, infrequent subcutaneous injectable to reduce barriers to treatment.

Innovation in care and research - Preparing for new AD treatments

P30. Preparing for new AD treatments

P30-05Are anti-amyloid treatments for Azheimer's disease ready for practice? long-term effectiveness and cost-effectiveness in Europe

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Introduction: Recent trials on anti-amyloid treatment for early Alzheimer's disease (AD) have shown significant effects on symptoms, albeit below what some consider clinically meaningful, with potential for adverse events. Potential high drug prices raise questions regarding budget impact, likely competing with alternative care and support for people with dementia. Cost-effectiveness estimates are available for the US but lacking for Europe, hindering preparations for these treatments. We aim to estimate the cost-effectiveness of anti-amyloid treatment for early AD in Europe.
Methods: We developed an open-source health-economic decision model to simulate the lifetime health-economic effects of lecanemab anti-amyloid treatment on reducing disease progression in people with a diagnosis of mild cognitive impairment or mild dementia with abnormal amyloid. Treatment effect was 31% reduction in risk of transition to (a more severe state of) dementia at current US list price of €24,000 per year continued through moderate dementia. Quality of life and care use across 5 European regions were used. The model is freely available at https://github.com/ronhandels/ipecad.
Results: Anti-amyloid treatment resulted in mean per-person lifetime quality-adjusted life year (QALY) gains (range over 5 regions 0.33-0.39) and care costs/savings (range €-146 to 7,864) at additional diagnostic and drug costs (€113,000). Incremental cost-effectiveness ratios (ICER) ranged from €277,000 to 309,000 per QALY gained. Headroom analysis indicated treatment was potentially cost-effective across regions at €7,495-9,800 per year. Scenarios of stopping earlier after 24 months without and with assumed sustained treatment effect and treatment effect waning of 10% per year indicated uncertainty (ICER ranged €78,188-433,357 per QALY gained). Discussion: Anti-amyloid treatment lecanemab for early AD at the current US price exceeds common willingness-to-pay thresholds in Europe. We recommend efficient early AD identification, lower price, and performance-based payment, along with research on cost-effective AD subtypes using current trial data, for anti-amyloid treatment to reach cost-effectiveness thresholds in Europe.

Policy - Legal and ethical issues

P31. Legal and ethical issues

P31-02The constellation of older adults with dementia under guardianship in the Netherlands: a court file study

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Vrije Universiteit Amsterdam

Background: As the Dutch population ages, the prevalence of dementia rises, affecting a growing proportion of older adults in the country. A progressive condition like dementia may cause a gradual decline of decision-making capacity. For older adults with dementia who experience a loss of decision-making capacity, alternative mechanisms may become necessary to provide the adult with the support needed to make his own decisions and when this is not or no longer possible. Some older adults may even require a court-ordered guardianship measure, resulting in a limitation of their legal capacity and compromising their autonomy. In order to properly support and protect the specific interests of these older adults, it is important to gain insights into the relevant internal and external factors resulting in the appointment of a legal guardian.
Methods: In order to study the constellation of older adults with dementia placed under guardianship in the Netherlands, we analyzed 906 guardianship court files from four different district courts in the Netherlands. We collected both quantitative and qualitative data. Using thematic content analysis, we aimed to identify the relevant factors that lead to the appointment of a legal guardian within this group of older adults.
Results: Preliminary results will be presented during the Alzheimer Europe Conference (34AEC), as the research will be concluded in June of 2024.
Conclusions: First conclusions will be presented during the Alzheimer Europe Conference (34AEC), as the research will be concluded in June of 2024.

Policy - Legal and ethical issues

P31. Legal and ethical issues

P31-03Documenting driving risks in a UK based mental health crisis team for older people including people with dementia - a complete audit cycle

Leena Reddy
Dr Leena Reddy - delegate

Driving forms an important part of an older person's independence including for those living with dementia. For a community multidisciplinary mental health crisis team, it is crucial to ensure patient safety and inclusivity by ensuring risk assessment and management are in keeping with the Driver and Vehicle Licensing Agency guidance along with appropriate consent around information sharing.

To ensure the above quality standards were being met, the Newbury crisis team conducted a complete audit cycle into the documentation of driving issues on the electronic patient notes.

The audit tool included the presence and quality of documentation concerning driving status, concerns from patient and carers, driving offences, consent around information sharing with the DVLA and family, cognitive function, risk of suicide or harm to others, medication side effects that may affect driving, substance misuse, advice given and care planning, including communication with the general practitioner and a robust discharge handover ensuring follow up.

The initial audit indicated there was scope to improve documentation. Recommendations implemented included presentation of findings for staff views, devising improved documentation in a busy ward round in the form of a template, and staff training around DVLA guidance along with staff training sessions and DVLA guidance and patient and carer information leaflet availability on the shared drive for quick reference.

The re-audit showed significant improvement in documentation of driving issues. However, there remained scope for improvement in documenting side effects from medication, suicide risk and substance misuse. Recommendations implemented following the re-audit included refresher educational training to staff, boosting staff confidence in gathering information with reassurance from doctors of their availability for support and decision making, and a further bite size prompt incorporated into the ward round template including key areas needing further improvement in documentation. We hope to re-audit further in a year's time.

Policy - Legal and ethical issues

P31. Legal and ethical issues

P31-05Developing good practice guidance for dementia services: a World Health Organization project

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[1]University of Nottingham, [2]World Health Organization

Background: It has been well-documented that people living with dementia are often unable to fully exercise their rights in care services. This includes being excluded from the community and being unable to make decisions relating to their own care. As a result, the World Health Organization (WHO) launched their 'Global action plan on the public health response to dementia 2017-2025' (WHO, 2017). This plan aims to improve the lives of people with dementia, their care partners, and families. A separate WHO project involves

developing a good practice guidance document of global dementia services that provide good rights-based and person-centred care.
Objective: To systematically develop the good practice guidance document outlined by the WHO.
Methods: Our project involves several stages: 1) identification of potential services using networks, internet searches, and an international survey; 2) screening services against minimum service criteria; 3) obtaining contact details of services that pass initial screening; 4) providing potential services with a template to obtain information regarding human rights; 5) classifying services into seven different categories; 6) full screening against human rights criteria and evidence for rights-based practices within each category; 7) full write-up of highest ranking services; 8) validation of selected services as good practices through peer-review, and; 9) an international consultation of the final document draft before launching.
Results: We currently have around 450 services left from 1014 previously screened. We are aiming for two services within each service category within the final document. These services will demonstrate good practice in relation to human rights.
Implications: This project will demonstrate the progress made by services to ensure the human rights of people living with dementia are protected and guaranteed. It will also show other services not included within the document how changes can be implemented to ensure the full enjoyment of rights.

P32. Alzheimer Switzerland - Preparing for new horizons

P32. Preparing for new horizons: best practices in Switzerland

P32-01Joined forces for better care: the cooperation of Swiss Memory Clinics and Alzheimer Switzerland

Stefanie Becker[1], Julius Popp[2]
[1]Alzheimer Schweiz, [2]Swiss Memory Clinic

The symposium will showcase the implementation and initial products of a cooperation between the association of the Swiss Memory Clinics and Alzheimer Switzerland as patient organisation. This cooperation represents an important preparation for ensuring optimal care in light of the new therapies to come.

Swiss Memory Clinics and Alzheimer Switzerland pursue the common goal of improving the healthcare and quality of life of people with dementia and their relatives. To achieve this,

they have decided to join forces in 2021 within the framework of a cooperation. Our mutual objectives are:

1. The organisations support each other in political projects, focusing on national healthcare, tariff and social policy as well as cantonal healthcare policy. The aim is to provide high-quality, adequately funded healthcare by well-trained staff.
2. closer co-operation in medical and social care in order to provide people with dementia and their relatives with the best possible information, guidance and support. Networking should ensure continuity and coherence and improve the quality of life of those affected.
3. mutual support in media representation to increase awareness of the organisations and their cooperation and to draw attention to the challenges of optimal healthcare.

The symposium will show the implementation and initial products of the co-operation, which also represent an important preparation for ensuring optimal care in the light of the new therapies to come.

In addition to inputs, a panel of experts will address the most important questions that such active cooperation can answer in order to provide answers for the new horizons in Alzheimer's diagnosis and care.

P32. Alzheimer Switzerland - Preparing for new horizons

P32. Preparing for new horizons: best practices in Switzerland

P32-02Best practice strategies for implementing a personalized dementia care plan: Insights from the collaborative role of Alzheimer association in the swiss memory clinics.

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In the last decade, memory clinics have made significant successful efforts in identifying the first signs of cognitive decline and initiating dementia-specific diagnostics and treatments. Additional work is still required to manage the complex post-diagnostic support. Recent evidence underlines that a

collaborative management care strategy may be clinically efficient and cost-effective, by decreasing health utilization, reducing hospitalizations, delaying institutionalization, and improving patient and caregiver quality of life. To reach this goal, Alzheimer Switzerland (Alz-ch) and the Swiss memory clinics (SMC) associations have joined their efforts in a mutual and structured collaboration to provide high-quality coordinated care in a targeted manner. In our speech, we provide examples of good practice for a personalized and comprehensive dementia care plan. We illustrate how nurses and social workers from Alz-ch are an integral part of this collaborative management care. As soon as the diagnosis is announced, Alz-ch provides patients and caregivers with personalized advice concerning illness, daily organization and questions relating to social laws, and help them cope with the daily life changes. We further underline how the presence of Alz-ch in the memory clinic may ensure an earlier involvement in the care process, through a coordination with the multidisciplinary interventions (cognitive/speech therapies, patient and/or caregiver psychological therapies). In some SMC, a care manager realizes a comprehensive needs assessment and coordinate multidisciplinary interventions. Here, again, the pivotal role of nurses and social workers from Alzh-ch and their closer collaboration with the care manager may allow a rapid reorientation of care considering the patients and caregivers' specific needs. It further allows transferring the interventions benefits from the memory clinic to the daily life through either social and leisure activities or specific interventions at home. These examples recognize the complementarity of Alz-ch and the SMC to work together in the field of medical and social care.

P32. Alzheimer Switzerland - Preparing for new horizons

P32. Preparing for new horizons: best practices in Switzerland

P32-03The Swiss Memory Clinics diagnostics recommendations

Julius Popp
UZH

The timely and accurate diagnosis in people developing cognitive disorders is essential for personalised counselling, treatment, and care. The Swiss Memory Clinics association has defined and published national quality standards for the assessment of cognitive disorders for the first time in 2018 and updated them in 2023-2024. These recommendations include all topics relevant for clinical practice related to the diagnostic workup of cognitive disorders. The main objectives of the recommendations are to enable personalised high-quality early and differential diagnosis throughout Switzerland, and to offer practical guidance for clinicians in both primary care and memory clinics.

P32. Alzheimer Switzerland - Preparing for new horizons

P32. Preparing for new horizons: best practices in Switzerland

P32-04Recommendations of the Swiss Memory Clinics for the treatment of dementia

Stefan Klöppel
UPD, Universitätsklinik für Alterspsychiatrie und Psychotherapie

Non-pharmacological interventions gain importance in the symptomatic treatment of dementia. Increasing evidence concerning their effectiveness as well as an increasing amount of negative data on the effects of neuroleptic drugs underlie this trend. New antibody treatments may decrease the number of cases.

Over the past two years, Swiss memory clinics developed a treatment standard for dementia, in addition to standards for the diagnostics of dementia and the treatment of behavioral symptoms. Representatives of many stakeholders where specialties were integrated and the result is now freely available in three national languages Nationale Plattform Demenz (https://www.bag.admin.ch/bag/de/home/strategie-und-politik/nationale-gesundheitsstrategie/demenz.html#292691039).

The practical implementation is challenged by a shortage of qualified staff and an insufficient reimbursement system for this kind of service. Improved interfaces between settings, hometreatment and remote diagnostics and therapy may provide solutions.

P32. Alzheimer Switzerland - Preparing for new horizons

P32. Preparing for new horizons: best practices in Switzerland

P32-05Panel discussion: new therapies, new target groups and questions

Stefanie Becker[1], Julius Popp[2], Stefan Klöppel[3], Christian Chicherio[4],

Sandra Oppikofer[5]
[1]Alzheimer Schweiz, [2]Swiss Memory Clinic / University of Zurich, [3]Swiss Memory Clinics / University Clinic of Bern, [4]Swiss Memory Clinic / University of Geneva, [5]Alzheimer Switzerland / University of Zurich

Counselling and support for people with dementia are the most important aspects of good quality of life and care. Promising non-invasive biomarkers and new disease-modifying therapies open perspectives but also pose a whole bunch of new questions to which the association Swiss Memory Clinics and Alzheimer Switzerland seek to find answers together. What are the most important issues and the target groups –patients, their relatives, healthcare providers - facing them?

Experts from both organisations will discuss some of the most important questions to find common answers and set the ground for their future collaboration in the light of the new horizons in dementia therapy.

Patient pathways - Hospital care

P33. Hospital care

P33-01The use of restrictive practice and restraint in the care of people living with dementia during a hospital admission: findings from an ethnographic study

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People living with dementia are at significant risk of experiencing restrictive practice or restraint during an unscheduled acute hospital admission, however it has remained an unexplored feature of routine care. In the UK, hospital data recording the use of restrictive practice is patchy and inconsistent, highlighting that these practices are poorly recognised and under reported, to the detriment of high-quality care.
This paper draws on 225 days of ethnographic (observational) research exploring the use of restrictive practice in the care of people living with dementia across a hospital admission.

Our observational data was collected over 18 months from nine wards in three regions of England, covering a range of geographies and socio-economic demographics. In each region an assessment unit (30 days), an older persons care ward (30 days) and a specialist mental health ward (15 days) were observed, alongside in-situ interviews with patients and staff delivering care.
This study identified restrictive practice as an invisible but everyday feature of care experienced by all people living with dementia within hospital wards. While quantifiable and visible restraint (physical restraint, pharmaceutical sedation, legal frameworks) was observed, our findings highlight that hidden, unrecognised, and unrecorded, restraint was experienced by all people living with dementia within hospitals. This encompassed a wider range of routine practices, staff attitudes, and ward cultures of control, during care. People living with dementia are expected to remain in bed or at the bedside across an acute hospital admission, with opportunities to leave the bedside further reduced when restrictive practices were applied, with significant impacts on the person, contributing to high levels of distress, and poor outcomes. This paper will explore these cultures of care and alternative approaches to improve the experiences of a hospital admission for this significant and vulnerable population within our hospitals.

Patient pathways - Hospital care

P33. Hospital care

P33-02Carer rated quality of hospital care and personal information documents for people with dementia

Chloe Hood, Chloe Hood, Kashish Janiani Tulsiyani
Royal College of Psychiatrists

Background: The National Audit of Dementia (NAD) collects data from general hospitals in England and Wales related to the quality of care. The most recently published report in 2023 collated information from patient records of people with dementia, feedback directly from family carers, and organisational information relating to care provision. The Dementia-Friendly Hospital Charter promotes the use of personal information documents (PID) or patient passports, which contain information about the person with dementia's preferences as well as care needs, and support staff in providing person centred care. As part of the audit, hospitals were asked to carry out a spot check on a randomly selected 10 patients with dementia across 3 wards to see whether their PID was at the bedside visible to staff providing care. Hospitals also distributed questionnaires to family carers of people with

dementia. The questionnaire has been used over 3 rounds of audit and produces a score for carer-rated quality of care.
Method: To examine whether use of the patient passport had an impact on the rating of care, we carried out secondary analysis post reporting. For each hospital, we compared the carer scores with the proportion of patients with dementia who had a PID in place. Carer scores ranged from 32-90, and patients with PID from 0-100%.
Results: 73 hospitals had a result from the bedside check exercise, plus sufficient carer questionnaires to produce a score. Correlational analysis showed that there was a significant association between higher carer ratings and a greater proportion of patients with a PID in place, $r(71) = 0.230$, $p = 0.025$.
Conclusion: Use of a PID/ patient passport is associated with a higher carer rating of care for people with dementia, and this supports the assumption that PIDs assist staff in providing better quality care.

Patient pathways - Hospital care

P33. Hospital care

P33-03Patients' evaluation of information provision during the diagnostic trajectory at the memory clinic

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Background: We examined how patients evaluated the information provided during their diagnostic trajectory in a tertiary memory clinic.
Methods: Between February 2021 and June 2023, 802 patients (65±8yrs, 38%F, MMSE: 26±4, N=401(50%) SCD, N=117(15%) MCI, N=207(26%) dementia (AD: N=156(75%); non-AD: N=51(25%), N=77(10%) other)) of Alzheimer Center Amsterdam completed a questionnaire to evaluate the information provided during their diagnostic trajectory. We assessed satisfaction with the amount of information, perceived helpfulness (1-4 point Likert scale), wish for more/less information (yes/no), and which information was missed/redundant (open-ended). With Kruskal-Wallis, χ^2, linear- and logistic regression, we tested effects of: time (years) between first visit and questionnaire completion (median(IQR): 3.2(0.1-6.3) years), syndrome diagnosis, etiological diagnosis (AD vs non-AD dementia), age, gender, MMSE, and education. Open-ended questions were analyzed

using thematic content analysis.
Results: Patients were satisfied with the amount of provided information (3.1±0.8) and perceived information as helpful (3.1±0.9), with no differences based on syndrome (p=.99; p=.50) or etiological (p=.72; p=.57) diagnosis. Time was negatively associated with both satisfaction with the perceived amount (.03 point/year) and helpfulness (.04 point/year) of provided information (p-values<.001). We found no significant associations with age, gender, education, and MMSE (all p-values>.05). A quarter (214/802(27%)) of patients indicated a wish for more information, in particular patients with higher MMSE scores (p=0.01). In total, 225 information needs were reported, thematically grouped into: information about test results (70/225(31%)), diagnosis (66/225(29%)), practical implications (50/225(22%)) and diagnostic testing (11/225(5%)). Additionally, needs were expressed regarding the way information was provided (28/225(12%)). Only few (18/802(2%)) patients in hindsight preferred less information.
Discussion: A vast majority of tertiary memory clinic patients evaluated the information provided during the diagnostic trajectory positively. A quarter indicated a need for more information. Improvements can be made by actively and recurrently checking information needs, and providing information accordingly.

Patient pathways - Hospital care

P33. Hospital care

P33-04Microlearning and person centred dementia care

Gillian Teague
DSIDC

In this presentation, I will outline the development, rollout and findings or our person-centred dementia care microlearning course for all patient-facing staff.
Person centred care (PCC) appears to make a difference to how well people with dementia manage on hospital wards (Scerri et al., 2020). Furthermore, the term PCC is used widely in health and social care services, yet there are health professionals who find PCC difficult to define and demonstrate in their practice (Byrne et al., 2020). Therefore, we identified the need to design a course to facilitate the continued development of meaningful interactions between hospital staff and people with dementia. The new course demonstrates how staff can use key elements of Kitwood's (1997) PCC approach in their day-to-day practice.
Due to personnel shortages and increasing demands on their time, it is becoming harder for hospital staff to be released for half-day or full-day training courses. With this in mind, the

DSiDC team sought innovative time-efficient ways to provide dementia education to hospital staff. A microlearning educational delivery model, 7taps, was adopted. Microlearning delivers short pieces of content in easily understandable ways of utilising a variety of methods such as: video, short written text, flashcards, games and quizzes. Accessed by a QR code, staff can complete the education on their mobile phone, tablet or computer at a time, place and pace that suits the individual. The PCC course is divided into four stand-alone modules using clear, uncomplicated language. The course concludes with a questionnaire that will allow the evaluation of it's effectiveness.

Patient pathways - Hospital care

P33. Hospital care

P33-05Physical activity interventions for hospitalised patients with dementia: systematic review

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Introduction: People living with dementia are vulnerable to adverse outcomes of hospitalisation, such as deconditioning and functional decline. The aim of this review was to examine the effectiveness of hospital-based interventions involving physical activity at reducing physical deconditioning in hospitalised patients with dementia.
Methods: Five databases (MEDLINE, the Cochrane central register of controlled trials [CENTRAL], Embase, PsycINFO, CINAHL) were searched from inception to December 2023 to identify eligible studies. Two researchers independently carried out screening, data extraction and quality assessment. Inclusion criteria were adults with a documented diagnosis of dementia (all aetiologies) admitted to hospital following an acute event. Interventions increasing physical activity levels during the hospitalisation period were eligible. Where studies included participants where only a subgroup had dementia, study authors were contacted to request unpublished data. Data were synthesised. Prospero registration: CRD42023482947.
Results: 2040 records were identified, of which 6 studies (584 participants with dementia) were included. One was a randomised controlled trial, 5 were non-randomised controlled

trials conducted in the following settings: acute care for elders unit (n=2), acute psychogeriatric ward (n=2), internal medical unit (n=1) and geriatric rehabilitation ward (n=1) across 6 countries. Dementia severity was largely mild-moderate (severe recorded in 1 study). Three studies included a single component intervention and 3 studies included physical activity as part of a multicomponent intervention (other components were music-based: n=1, cognitive: n=1 and health education: n=1). Different types of physical activity were included; all studies included walking and a strength/resistance component. Other elements included balance (4 studies) and flexibility (2 studies). Outcomes included activities of daily living, strength, and falls. We are currently awaiting two datasets and response from additional study authors; final results will be available at the time of the conference.
Conclusion: The evidence concerning physical activity for people with dementia who are hospitalised is limited.

Living with dementia - Relationships and sexuality

P34. Relationships and sexuality

P34-01Loneliness in the middle of the crowd: the experience of loneliness in people with dementia living in residential long-term care

Doris Gebhard
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Social relationships influence the mental, cognitive and physical health of people with dementia. The evidence base for loneliness in people with dementia is very limited, particularly for the unique social environment of residential long-term care facilities. This study aims to help better understand how people with dementia experience loneliness in order to provide a basis for more targeted interventions.
Qualitative interviews were conducted in six residential long-term care facilities in Germany. The interview guide was based on the 3-item UCLA loneliness scale, supplemented by open questions on the experience of social life in the facility. The transcripts were analyzed using qualitative content analysis. Inductive and deductive category development was applied.
A total of 93 people with dementia (age: mean value = 85.87 years; 78.49% female; MMSE mean value = 17.97) participated in the interviews. 32.2 % of respondents experience a lack of company, 25% feel isolated and 23.8 % feel left out. The most frequently mentioned reasons for experiencing loneliness are (1) a lack of opportunities for social interaction, (2) a

lack of suitable partners for socialising and (3) the feeling of being rejected by others. The top three reasons mentioned by respondents for not feeling lonely are (1) the sufficient availability of opportunities for social interaction, (2) the rejection of social contact with others and (3) the preference for preoccupation with oneself.
The results provide a deeper insight into the experience of loneliness among people with dementia living in residential long-term care facilities. The perceived reasons for the presence or absence of loneliness are closely related to the social environment (opportunities for social interaction), but also to the attitude that residents with dementia have towards their peer residents. This points to new approaches for interventions that address the structural and attitudinal determinants of loneliness in residential long-term care.

Living with dementia - Relationships and sexuality

P34. Relationships and sexuality

P34-02The effect of a person with dementia's permanent nusing home admission on their partner's mental well-being

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For many persons with dementia (PwD), transitioning to a permanent nursing home (NH) becomes inevitable at some point and can have a substantial impact on both the PwD and their partner. This study examines the effect of a PwD's permanent NH admission on their partner's mental well-being. Survey data (collected between September and December of 2016 and 2020, n=6,319) assessing well-being in terms of (1) risk for anxiety and depression, (2) social and emotional loneliness, (3) ownership over one's life, (4) stress and (5) caregiver burden is linked on the individual level to Dutch administrative data on long-term care use and health. A cross-sectional event study methodology is combined with inverse probability weighting to estimate the causal effect of transitioning to a nursing home. Preliminary results indicate that both risk for anxiety and depression and loneliness are at its highest right before the PwD's NH admission, decreasing immediately after institutionalization. Partners signal ownership over their lives to be at its lowest one period prior to institutionalization, after which it increases again. Both stress and caregiver burden reach a peak around the time of institutionalization and decrease again after the PwD has been living in the NH for 6 months. Increased stress levels are caused by concerns related to caregiving and the relationship with their partner. Although levels of stress and caregiver

burden eventually decrease again, it is important to note that they do not reach levels as low as the >1 years prior to admission. These results imply that NH placement of a PwD can yield a certain degree of relief for their partner. However, as caregiving continues after institutionalization, so does the stress and burden associated with it. It is therefore important to adequately support partners of PwD during this transition as well as in the proceeding years.

Living with dementia - People living with dementia

P34. Relationships and sexuality

P34-04Shimmering lights: the lived experience of gratitude for dyads of people living with dementia and informal caregivers

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[1]Radboudumc, [2]

Background and Objectives: Gratitude, the awareness of the beneficial aspects of life and the goodness of others, is related to improved mental health. Gratitude research is a quickly growing field of positive psychology, but the concept of gratitude has thus far only been sparsely considered in dementia literature. This study aimed to explore the lived experience of gratitude among dyads of people living with dementia and their informal caregivers.
Research Design and Methods: Individual semi-structured face-to-face interviews were conducted with 18 Dutch participants: 9 dyads of community-dwelling people living with dementia (age 75-92 years, 56% female) and their informal caregiver (i.e., partner, daughter, or friend, age 46-80 years, 78% female). Interviews covered the phenomenon of gratitude, experienced in general and within the dyad. The interviews were audio-recorded, transcribed, and interpreted using a phenomenological hermeneutical approach. A naïve understanding was formulated, followed by a structural analysis of the transcript in relation to the naïve understanding.
Results: For people with dementia and caregivers meanings of gratitude could be understood as positive feelings, positive attitudes, and a positive character trait. It was described as looking back on the past with satisfaction and appreciation, and consciously enjoying positive things in the present. Gratitude meant having the idea of doing relatively well, also compared to others. Gratitude had a relational aspect: enjoying things together in the dyad and appreciating each other, both of which can be implicitly or explicitly. Gratitude also meant feeling connected to something bigger, such as God or the Universe.

Discussion: Exploring meanings of gratitude for dyads of people living with dementia and informal caregivers could contribute towards implementing this positive construct in research and practice.

Living with dementia - Empowerment and self-management

P34. Relationships and sexuality

P34-05The centrally accompanied, comprehensive implementation of the German expert standard "Relationship management in the care of people with dementia" in 225 nursing homes

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Korian Deutschland GmbH

Objective: The centrally accompanied, comprehensive implementation of the German expert standard "Relationship management in the care of people with dementia" (the expert standard is a German guideline for caregivers) in 225 nursing homes
Target group(s): People with dementia in need of care and their relatives/caregivers; employees of outpatient and (semi-) inpatient services/facilities
Project content: Based on the experience gained from the successful implementation during a pilot project with a fully inpatient nursing home in 2022/23, the rollout for the comprehensive implementation of the expert standard in over 250 facilities/services was planned and supporting documents were developed. These documents serve to support the facilities/services in implementing the expert standard within the facility/service. A manual uses the DNQP's phase model (DNQP=German Network for Quality Development in Nursing) to guide through the implementation process and provides important information which is crucial for a successful and sustainable implementation. To facilitate the transfer of theory to practice, further explanations, specific implementation examples and measures are depicted in an additional document. Flyers on topics relating to the expert standard were developed and made available. Six dementia parcourses were also purchased for the implementation process, which enable staff to gain self-awareness and reflect on their own person-centered approach. For the comprehensive implementation, the facilities/services were able to set the implementation start date for 2024 themselves in order to be able to choose the most suitable implementation period. The facilities/services are supported centrally through monthly kick-off calls. Specific questions about the implementation

process and the expert standard can be asked in a regular, voluntary consultation hour. Results of the project: Preparation of the comprehensive and sustainable implementation of the expert standard "Relationship management in the care of people with dementia" based on the experiences of a pilot project supported by the central quality management department.

P35. INTERDEM Advance care planning and shared decision-making in dementia

P35. Advance care planning - INTERDEM

P35-01Survival and determinants of mortality in nursing home residents with young onset dementia: insights from BEYOnD and Care4Youngdem

Raymond Koopmans[1], Jasper Maters[2], Jenny van der Steen[2], Marjolein de Vugt[2], Ans Mulders[2], Christian Bakker[2]
[1]Radboudumc, [2]

Background and aim: Young Onset Dementia (YOD) is associated with a reduced life expectancy. However, studies concerning survival in people with YOD are sparse and there are no studies reporting about survival after admission to a nursing home. Our aim was to examine survival time, determinants of survival and causes of death in nursing home residents with YOD. Methods: Survival data were obtained from the BEYOnD- and Care4Youngdem-study. Both studies provided samples from YOD special care units. Residents were followed until death or census date. Causes of death were retrieved from medical records and surveys. Kaplan-Meier curves were plotted to analyze survival times after diagnosis and admission. Cox proportional hazards regression models were composed to investigate determinants of survival, including sex, age, severity and type of dementia, and comorbidities. Finally, the hazard ratio (HR) of the independent determinants in the combined samples were assessed. Results: 138 (73.8%) residents of the BEYOnD-sample and 121 (58.8%) residents of the Care4Youngdem-sample died during follow-up. Median survival time after diagnosis was 9.0 (95% CI 7.8-10.2) and 8.1 (95% CI 7.1-9.0) years in BEYOnD and Care4Youngdem, respectively. Median survival time after admission was 6.3 (95% CI 5.3-7.2) and 4.9 (95% CI 4.3-5.5) years. Survival times did not differ significantly between the cohorts. Type and severity of dementia were found to be associated with mortality. The most common primary causes of death were dehydration/cachexia (29.9%) and respiratory infection (24.1%). Discussion: Our study shows a longer survival of YOD patients living in long term care facilities compared to studies in residents with late onset dementia.

Implications for practice and future perspectives: Survival data of YOD patients may be relevant in the context of prognostication and thereby advance care planning. Future studies could focus on predictors of survival time after admission in order to develop a prediction tool.

P35. INTERDEM Advance care planning and shared decision-making in dementia

P35. Advance care planning - INTERDEM

P35-02Planning for a future with dementia: the need to go beyond the medical aspects in advance care planning

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Advance care planning (ACP) is essential for people with dementia and their families. According to them, it is also important to discuss ACP together in the family context. This is primarily due to the cognitive decline experienced by people with dementia, which eventually requires family caregivers to make decisions on their behalf. In an interview study, people with young-onset dementia and their caregivers stressed the need for a holistic approach that combines medical, social, and mental health elements.

The European Working Group of People with Dementia also underlined the importance of focusing on social care and future priorities. They highlight the essential role of families and trust-based relationships in these discussions and the need to move beyond a purely medical focus. One of the Working Group participants said: *"I think when we talk about advance care planning there's a concentration on how we are going to leave this world. Advance care planning to me is how we're going to live in the world as well…"* This need aligns with the public health approach to ACP that aims to normalise conversations about end-of-life preferences, death, and dying and the need to support conversations in the family context

In a mixed-method evaluation study on a website to support people with dementia and their families in ACP in the family context, we found that interactive online tools can support these ACP conversations in the family context. They can help people with dementia and their families to initiate and engage in meaningful ACP discussions addressing the social and medical aspects of their future needs. Future research should focus on how these conversations in the family context can support ACP between the person with dementia, their family caregiver and the healthcare professional.

P35. INTERDEM Advance care planning and shared decision-making in dementia

P35. Advance care planning - INTERDEM

P35-03Tensions in conceptualizing advance care planning with dementia

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Advance care planning involves making choices on what is most important for people to guide future decision making. It can help clarify tradeoffs in the case choices conflict and it is impossible to have it all. Therefore, considering tensions is inherent to advance care planning. However, there are also tensions in conceptualizing advance care planning for people with dementia and their family caregivers. Popular generic definitions of advance care planning limit to people with decision-making capacity to decide about their future self but do not refer to realities of people with limited, declining or fluctuating decision-making capacity who are still capable of changing their preferences or their view on what is important in life. Involving family caregivers is important for them to understand the preferences and to consider impact of decisions on them or on the relationship between the person with dementia and their family caregiver. To what extent is advance care planning a person-centered process or a relationship-centered process that is inclusive of family caregivers? Another tension concerns a generic definition of advance care planning that is inclusive as it applies to anyone versus a specific definition that applies optimally to persons with dementia. To what extent are these definitions considered inclusive and what are benefits of either approach? Examples from recent research will be highlighted to elicit tensions in advance care planning in dementia and challenging in conceptualizing it.

P35. INTERDEM Advance care planning and shared decision-making in dementia

P35. Advance care planning - INTERDEM

P35-04Ethical dilemmas in patients with shifting mental capacity

Rozemarijn van Bruchem-Visser
Erasmus MC

In patients with cognitive disorders, mental capacity can shift over the course of the disease. This poses questions in both research as medical decisions. To complicate matters even more, in the course of dementia, a new individual can emerge, with sometimes wishes and preferences that are not totally in line of even opposite of previous expressed choices. Often, family will try to uphold the decision expressed by "the old me", where researchers and clinicians are obliged to take into account the interests of "the new me".

Where a diminished mental capacity is more or less expected in older patients with cognitive disorders, in younger patients this is often acknowledged later on in the disease. As a result, sometimes drastic decisions have already been made in the time prior to the diagnosis of for instance frontotemporal dementia, posing serious problems for both patients and their loved ones.

Assessment of mental capacity and weighing the interests of the old versus the new me are crucial in the care for (younger) patients with cognitive disorders.

P35. INTERDEM Advance care planning and shared decision-making in dementia

P35. Advance care planning - INTERDEM

P35-05Lived experience of advance care planning and shared decision making

Orii McDermott[1], Chris Roberts[2], Jayne Goodrick[3]
[1]University of Nottingham, [2]Alzheimer Europe, [3]

This conversation-style session explores personal experiences of advance care planning. We will discuss the importance, as well as challenges, of planning our future ahead based on our personal experiences. We will share what worked well for us but will also highlight what can be done more to support shared decision making.

Inclusion and intersectionality - Public involvement in dementia research

P36. Public involvement in dementia research

P36-01Underserved populations in dementia research in Scotland

Emma Law
Neuroprogressive and Dementia Network

In this presentation, I will outline how we are addressing the issue of including underserved groups in research, within the Neuroprogressive and Dementia research Network (NDN) in Scotland.

We have identified a number of groups who we think are not well represented in research and we have taken strides to include these groups – I will show some of the ways that we have done this including travelling to some of our remotest areas in Scotland such as the Scottish Isles of Shetland in the North and Lewis in the West.

I will outline how we have identified and targeted care homes within some of the most deprived areas within Scotland and encouraged them to become 'research ready' by joining Enabling Research in Care Homes (ENRICH Scotland).

We have started working in urban areas in Scotland, which house some of our most deprived populations. Our aim is to increase access to research opportunities.

I will talk about the plans we have to include the LGBTQ+ community in research in Scotland in both care homes and community settings.

I will talk about the challenges in trying to involve as many of our underserved communities as we can but within the limitations of time and staffing resources.

Inclusion and intersectionality - Public involvement in dementia research

P36. Public involvement in dementia research

P36-02How Public Involvement helped shape the Alzheimer Europe position paper on risk disclosure.

Soraya Moradi-Bachiller[1], Barry Northedge[2]
[1]Alzheimer Europe, [2]

Alzheimer's disease (AD) research has recently shifted its focus towards the development of diagnostic tools for earlier detection and risk prediction of dementia. There has also been increased attention on strategies to keep the brain healthy and reduce modifiable risk factors contributing to the disease's onset and progression. This shift would lead to an increased focus on testing new AD treatments in people at the early stages of the AD continuum. Within this context, people with no known cognitive problems or in the early stage of AD (i.e. Mild Cognitive Impairment (MCI) due to AD), could have their risk of developing cognitive problems or progressing to AD dementia predicted and estimated as part of the research study. These risk assessment tools could be ultimately implemented in clinical practice, where people could be tested for their risk of developing dementia.

Although dementia risk prediction is happening in research and may take place in clinical practice soon, there has been very little focus on the disclosure of such risk. To address this lack of focus on risk disclosure, Alzheimer Europe developed general and specific recommendations in collaboration with Alzheimer Europe's national members and the European Dementia Carers Working Group (EDCWG), who also serve as the Pattern-Cog Advisory Board. The recommendations that we will present were developed with the feedback provided by the EDCWG as part of the Public Involvement activities of the Pattern-Cog project and are aimed at both clinicians and researchers.

This presentation will provide an overview of the Alzheimer Europe position paper on risk disclosure and how Public Involvement helped shape its recommendations.

Barry Northedge, who is a member of the EDCWG and the Pattern-Cog Advisory Board, will be present and will refer to his experience in this work.

Inclusion and intersectionality - Public involvement in dementia research

P36. Public involvement in dementia research

P36-03Co-designing an easy-read measure of care-related quality of life: reflections on involving people living with dementia and their supporters

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One in 11 people over the age of 65 have dementia in the UK. As their dementia progresses some will need support from social care services to continue living lives of quality. The Alzheimer's Society estimates that 60% of people receiving homecare live with dementia. Care-related quality of life, measured by the Adult Social Care Outcomes Toolkit (ASCOT; www.pssru.ac.uk/ascot), is an outcome measure used internationally as an indicator of care quality. However, some older people find standard questionnaires difficult to complete due memory problems and other dementia-related challenges; this means their views and experiences may be excluded or never captured (Aznar et al, 2021).

We co-produced an 'easy read' version of the Adult Social Care Outcomes Toolkit (ASCOT), a questionnaire used to measure how social care affects people's quality of life, together with a working group of 8 older people, primarily those living with dementia and their supporters/carers. Changes made by the working group were tested in cognitive interviews with 25 older social care users who would normally struggle with standard questionnaires. We iterated this process over 6 Working Group meetings and 3 rounds of cognitive testing. The final version of the adapted toolkit is substantially different from the standard version.

Drawing on accounts of working group members, this presentation will focus on the process and results of involving people living with dementia and their carers/supporters in iteratively developing the new version of the tool. Not only is it achievable to successfully involve people living with dementia in the co-design of self-report outcome measures, but also people living with dementia and their supporters/carers find the process beneficial in a number of ways.

Inclusion and intersectionality - Public involvement in dementia research

P36. Public involvement in dementia research

P36-04Experiences and impact of involving family caregivers of people with dementia as public contributors to inform complex intervention development: a mixed-methods study

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[1]Uppsala University, [2]University of Exeter

Background: Meaningful public contribution in research can help maximise the potential of developing relevant, acceptable, and effective complex interventions. However, public contribution activities and the perceived impact of these activities are commonly poorly reported. We embedded a mixed-methods study of public contribution activities into the INVOLVERA study. The overall aim of the INVOLVERA study was to adapt a guided low-intensity behavioural activation intervention for people with dementia and depression. The aims of the embedded mixed-methods study were to explore: (1) the experiences of informal caregivers and research team members involved in public contribution activities; (2) the impact of public contribution activities; and (3) how to involve people with dementia in public contribution activities.
Method: A Public Advisory Group (PAG) consisting of wives and daughters of people with dementia (n=4), aged 44–71, with 5–9 years of caregiving experience. Nine PAG meetings were held to make sense of and interpret INVOLVERA study findings. Impact logs were completed during each meeting including ideas and suggestions made by PAG members and the perceived impact of public contribution activities. Semi-structured interviews with PAG and research team members are currently being conducted and analysed.
Results: In total, 161 ideas and suggestions were made by PAG members and recorded in impact logs, with 81% fully or partially implemented into the research. Ideas and suggestions included: reducing the amount of written intervention material to reduce complexity; adapting intervention illustrations to better reflect Swedish culture; and increasing the diversity of people with dementia and caregivers included in intervention case stories.
Conclusion: We hope findings will help: (1) strengthen the evidence base on the impact of public contribution; and (2) enhance understanding on how to best partner with public contributors. An important next step is to explore ways to involve people with dementia.

Inclusion and intersectionality - Public involvement in dementia research

P36. Public involvement in dementia research

P36-05Organizing a hackathon to promote collaboration between researchers and the public

Daní Püttmann
Alzheimer Nederland

Introduction: Involving the public in dementia research is a powerful tool to improve the relevance of research and its future implementation potential. However, for a lot of researchers it is difficult to find and work with target groups within the public. Alzheimer Societies have the network and communication channels to reach these groups. By organizing a hackathon, Alzheimer Nederland (The Dutch Alzheimer's Society) brought researchers and public together.
Method: A hackathon is a time-limited collaborative event where interdisciplinary teams converge to rapidly address specific challenges. These challenges were presented by different organizations that deal with dementia, such as a care home, a memory clinic and a day center for people with dementia. The teams consisted of two researchers paired with caregivers, students, data analysts and more. During the hackathon, each team received training in design thinking, consulted people with dementia and thought leaders and received guidance by mentors from a technical university with experience in design thinking.
Results: Following a brief online campaign, 35 individuals participated in our hackathon. Throughout the event, 12 researchers gained valuable firsthand experience in engaging the public. In the evaluation, these researchers highlighted the insightful nature of collaborating in diverse teams and communicating with individuals with dementia. Overall, the researchers rated the hackathon an 8.4 out of 10 on the evaluation scale.
Conclusion: A hackathon is a powerful tool to provide researchers with first-hand experience in public involvement in dementia research, both by working with diverse groups from the public in their teams and by involving people with dementia in multiple stages of their research. It is also an effective way to promote collaboration between researchers and Alzheimer Societies, utilizing the reach and communication power of the Alzheimer Society.

P37. CURE-ND: a united response to neurodegenerative diseases

P37. Cure-ND: A united response to neurodegenerative diseases

P37Cure-ND: Catalysing a United Response in Europe to Neurodegenerative Diseases

Siddharthan Chandran[1], Jenny Ceccarini[2], Théophile Bieth[3], Valentina Escott-Price[4]
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In 2019, four leading European neuroscience research institutes – Mission Lucidity (a partnership between KU Leuven, UZ Leuven, VIB and Imec in Belgium), the Paris Brain Institute (ICM, France), the German Center for Neurodegenerative Diseases (DZNE) and the UK Dementia Research Institute (UK DRI) – formed a new research alliance. As CURE-ND, "Catalysing a United Response in Europe to Neurodegenerative Diseases" , they represent a critical mass of over 2000+ researchers with a shared ambition to tackle the big challenges in neurodegeneration.

By pooling resources and expertise, together, these partners embrace a joint effort to accelerate the pace of scientific advancement and clinical applications in the field of neurodegenerative diseases, such as Alzheimer's disease (AD), to help patients and people at risk.

Every year, CURE-ND organizes multiple high-level scientific events to enable clinicians, scientists, and early career researchers to exchange expertise and know-how, to promote scientific collaboration, and to build a strong neurodegeneration researcher community in Europe and beyond.

The CURE-ND symposium, moderated by Prof. Siddharthan Chandran (Director UK DRI), will cover the aims and the ambitions of CURE-ND and will highlight some synergies and collaborative projects within our network. The panel discussion will raise attention to the need for long-term funding and support for global, collaborative dementia research efforts, aiming to stimulate innovation and drive progress in research, clinical care and prevention on Alzheimer´s disease.

Innovation in care and research - Telehealth and remote care

P38. Telehealth and remote care

P38-01Prevention of dementia using mobile phone applications (PRODEMOS) – a multinational randomised controlled effectiveness-implementation trial

Marieke Hoevenaar-Blom[1], Eric P Moll van Charante[2], Manshu Song[2], Sandrine Andrieu[2], Cindy Birck[2], Nicola Coley[2], Esmé Eggink[2], Jean Georges[2], Melanie Hafdi[2], Willem A Van Gool[2], Ron Handels[2], Anders Wimo[2], Youxin Wang[2], Carol Brayne[2], Wei Wang[2], Edo Richard[2]
[1]AMR, [2]

Background: The expected increase of dementia prevalence in the coming decades will mainly be within low-and middle-income countries and those with low socioeconomic status (SES) in high income countries. This study aims to reduce dementia risk factors in underserved high-risk populations using a coach-supported mobile health intervention. Methods: This open label, blinded endpoint, hybrid effectiveness-implementation randomised controlled trial (RCT) investigated whether a coach-supported mHealth intervention can reduce dementia risk in persons aged 55-75 years of low SES in UK or from the general population in China with at least two dementia risk factors. The primary effectiveness outcome was change in CAIDE dementia risk score after 12-18 months of intervention. Implementation outcomes were coverage, acceptability, appropriateness, adoption, feasibility, sustainability, fidelity, and costs using a mixed methods approach. Findings: Between 15th January 2021 and 18th April 2023, 1,488 persons were randomised (734 intervention, 754 control), with 1,229/1,488 (82·6%) available for analysis of the primary effectiveness outcome. After a mean follow-up of 16 months, the mean CAIDE score improved 0·16 points in the intervention group vs. 0·01 in the control group (Mean Difference (MD) 0·16, 95% Confidence Interval (CI) 0·03-0·29). The effect was larger in those who adhered to the intervention (MD 0·27, 95%CI 0·12-0·44) and those planning to change lifestyle (MD 0·33, 95%CI 0·10-0·57). Ten percent of those invited participated; of the intervention participants, 81% (593/734) adopted the intervention and 50% (367/734) continued active participation throughout the study. No differences in adverse events between study arms were found. Interpretation: A coach-supported mHealth intervention is modestly effective in reducing dementia risk factors in those with low SES in the UK and

any SES in China. Implementation is challenging in these populations, but those reached actively participated. Whether this will result in less cognitive decline and dementia requires a larger RCT with long follow-up.

Innovation in care and research - Telehealth and remote care

P38. Telehealth and remote care

P38-02Speech profile of cognitively normal adults with Alzheimer's disease related pathological changes

Rosanne van den Berg, Casper de Boer, Jessica Robin, William Simpson, John Harrison, Roos Jutten, Mariska van Liere, Lisa-Marie Schlüter, Argonde van Harten, Charlotte Teunissen, Elsmarieke van de Giessen, Frederik Barkhof, Lyduine Collij, Wiesje van der Flier, Sietske Sikkes

Introduction: Individuals with Alzheimer's disease (AD) often report word-finding difficulties as one of their first symptoms, indicating the importance of speech assessment for early recognition of subtle cognitive deficits. In this study, we assessed differences in speech characteristics between amyloid-positive and amyloïd-negative cognitively normal adults.
Method: Fifty cognitively normal adults from three clinical cohorts at the Alzheimer Center Amsterdam (46% Aβ-positive, 58% female, Age 68±6 years, Table 1) participated. Each individual completed tablet-based speech assessments for five consecutive days in their home environment. Speech tasks included picture description and journal-prompt storytelling. Daily administration time was 5-10 minutes. Speech features were automatically extracted from the voice recordings, such as hesitations, pronoun-to-noun ratio and average word length. We assessed whether speech characteristics differed between amyloid-positive and amyloïd-negative individuals, using linear regression models, adjusted for age, sex and education.
Results: We found that in picture descriptions the fraction of pronouns (B = 0.01, 95%CI =0.00 – 0.03, p = 0.007) and pronoun-to-noun ratio (B = 0.04, 95%CI = 0.00 – 0.07, p = 0.029) were higher in the amyloid-positive group (Mean ± SD, Mpronouns = 0.11 ± 0.02 , Mratio = 0.33 ± 0.06) than in the amyloid-negative group (Mpronouns = 0.09 ± 0.02, Mratio = 0.30 ± 0.05) (Figure 2). Other associations between speech features and amyloid burden were not significant.

Conclusion: We showed that free speech in cognitively normal amyloid-positive individuals differs from that of amyloid-negative individuals, specifically in the higher frequent use of pronouns, which might be an indicator of empty speech. This finding confirms the hypothesis that speech is affected in the earliest stages of AD. Our preliminary results indicate that spontaneous speech may be a relevant marker of subtle cognitive deficits in amyloid-positive individuals. As this technology can be employed remotely, it might be of particular value in decentralized trials.

Innovation in care and research - Telehealth and remote care

P38. Telehealth and remote care

P38-03Process evaluation of a multisite randomised controlled trial (RCT) evaluating the clinical effectiveness of the e-health intervention 'iSupport for dementia carers'

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A process evaluation was conducted alongside a large RCT in the UK of the World Health Organization's 'iSupport for dementia carers', an online self-help resource. It aimed to ascertain the usability and acceptability of iSupport; participant engagement and adherence to iSupport; contextual factors influencing its implementation and the extent to which iSupport may have changed behaviours beyond the intervention. Data collected from the intervention group (n=175) included qualitative interviews (n=52), post-intervention evaluation questionnaires (n=93) as well as 'access' data from the iSupport platform. The time that intervention group participants spent on iSupport was low. 22% of participants (n=32) did not spend any time on iSupport and 54% (n=94) spent between 30min. and 1.5 hrs. Qualitative data identified several factors driving this: time constrains (e.g., iSupport was described as an added task); issues linked to the self-directed online method of delivery (e.g., IT literacy, lack of feedback and interaction); issues regarding content and target

audience (e.g., carer level of experience). Positive impacts linked to time spent on iSupport were described. Firstly, participants, including those with extensive caring experience, reported how iSupport had made them feel reassured in how they approach their caring role. Secondly, participants felt valued and more able and entitled to ask for help and think about their own wellbeing. Finally, they reported feeling better informed with an improved outlook on their caring role and on the needs and feelings of the person living with dementia. This, in turn, was reported as leading to improvements in the dyad relationship. Evidence shows that the self-directed nature of iSupport had multi-faceted implications in terms of how much participants chose to engage with it. Results, which will be interpreted in the context of the results of the RCT, have wider implications for self-guided online interventions and the way these are implemented.

Innovation in care and research - Telehealth and remote care

P38. Telehealth and remote care

P38-04An online psychoeducation programme integrated with a virtual reality-based training for informal caregiver of persons with Alzheimer's disease: preliminary findings

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Introduction: Virtual reality (VR) is emerging as a useful tool for improving knowledge, empathy and self-efficacy in educational programmes. Our study aims to test the short- and medium-term effect of VR-based empathy training integrated into an online psycho-education programme.
Methods: 60 informal caregivers (iCGs) of people with mild-to-moderate Alzheimer's disease were randomised into a 6-week psychoeducational programme (control arm) or into the same psychoeducational programme integrated with a VR experience (experimental arm). During each two-hour psychoeducation session, the ICGs experience dementia symptoms from their loved one's perspective through the enjoyment of short VR videos. The VR-based experience is used to promote an empathic attitude. Before and after the intervention and again after 2 months, iCGs completed validate scales to assess burden

(ZBI), perceived stress (PSS), anxiety (STAI-Y1&2) and perceived self-efficacy for caregiving tasks (RSCSE). Linear mixed models were used to test the interventions effects. Results: 27 iCGs assigned to the control arm (age mean= 56; female:82%; children:63%) and 29 to experimental arm (age mean=54; female:79%; children:68%) concluded the intervention. The VR-based intervention decreased levels of burden (ZBI: t(28)=2.154; p=0.040; Cohen's d =0.400), stress (PPS: t(28)=2.177, p=0.038; Cohen's d=0.404), state anxiety (STAI-Y1= t(18) =2.400, p=0.23, Cohen's d = 0.446) and increase two domains of caregiving self-efficacy: responding to disruptive patient behaviours (RSCSE-RDB: t(28)=-2.358, p=0.026; Cohen's d=0.438), and controlling upsetting thoughts (RSCSE-CUT: t(28)=-2.126, p=0.042; Cohen's d=0.395). In the control arm, changes due to intervention did not reach statistical significance. In the experimental arm, levels of caregiver burden (p = 0.026), perceived stress (p < 0.001) and self-efficacy (p = 0.006) were maintained after two months.
Discussion: These preliminary results support the feasibility and the short- to medium-term effectiveness of an ehealth intervention integrating psychoeducation and VR experience. The intervention significantly reduces caregiver burden levels, perceived stress and state anxiety.

Innovation in care and research - Telehealth and remote care

P38. Telehealth and remote care

P38-05Delivering a blended eHealth intervention for carers of people living with dementia in the UK (CareCoach): findings from the CareCoach feasibility trial

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Around 700,000 family carers support 944,000 people living with dementia (PLwD) in the UK. Family carers provide significant support for PLwD often with limited support themselves. An intervention developed in The Netherlands, 'Partner in Balance' (PiB) which supports carers using a blended approach combining online resources with a health professional 'coach,' has been shown to increase self-efficacy, quality of life and reduce stress. We have adapted PiB for UK use (CareCoach) using Experience Based Co-Design and undertaken a multicentre randomised controlled feasibility trial to assess recruitment, retention, and outcome data completion as primary outcomes. Secondary outcomes include assessments of self-efficacy, psychological, health-related carer outcomes, and proxy health measures of the PLwD. An embedded qualitative sub-study will evaluate implementation and acceptability of CareCoach. Within four months, 42 family carers of PLwD were randomised to receive the CareCoach intervention over an 8-week period (n = 21) or usual care (n = 21). The CareCoach intervention group were allocated a coach to support the participant to work through jointly selected modules. Outcome data was collected remotely

at baseline; 6-months post-randomisation follow-up is now complete. Eight participants from the CareCoach intervention group took part in interviews to explore their experiences. Coaches took part in interviews and implementer group discussions to assess service implementation. We will present findings on the feasibility and implementation of CareCoach in the UK context. Findings will inform a subsequent definitive randomised controlled trial to test the clinical and cost effectiveness of the CareCoach programme to support family carers of PLwD.

Policy - Campaigning for change

P39. Campaigning for change

P39-01Don't leave dementia on the sidelines, the power of sports activities for people with dementia

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Sport has the power to unite. For people living with dementia, sports activities mean breaking isolation, creating a sense of purpose and strengthening self-esteem. Not only does actively participating in sport connect people, also supporting together enhances social inclusion and provides shared values. That is why the Flemish Alzheimer's Association (Alzheimer Liga Vlaanderen) developed a tailor-made program and campaign on this vital topic together with their 'Flemish working group of people with dementia'.
With tips and tricks and an educational program they want to motivate sports organizations to make their infrastructure and services dementia-inclusive. The goal: creating various initiatives to help people with dementia participate in or enjoy sports activities. We joined forces with partners who embrace our vision based on the guiding role of people with dementia and their informal caregivers as experts by experience. This led up to a unique collaboration between the Flemish Alzheimer's Association and the ProLeague, the governing body of all highest division football clubs at the national level in Belgium. This agreement is translated in a wide range of initiatives such as football memory sessions and young-onset dementia cafés in the clubs.
Efforts are also being made in other sports areas like dementia-friendly swimming and even in racing sports collaborations have been set up notably with the Circuit of Zolder and race car driver Bert Longin. During this presentation, the vision behind our dementia-inclusive sports activities will be presented together with a representative of our 'Flemish working

group of people with dementia'. We will focus on the lessons learned, look ahead towards ambitious future plans in the field based on the experiences of the person with dementia and launch the international version of the sports manifesto 'Step by Step', written by people with dementia!

Policy - Campaigning for change

P39. Campaigning for change

P39-02Involving the dementia community in campaigning for change at a European level

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In advance of the 2024 European Parliament elections, Alzheimer Europe and its member organisations launched a campaign to make dementia a priority in policy. The campaign includes three parts:

- Helsinki Manifesto: An outline of the current situation of dementia in Europe that details specific demands for the European Commission and national governments.
- A public Call to Action: Urging European policymakers to prioritise dementia and implement the actions in the Helsinki Manifesto.
- The Dementia Pledge 2024: Encouraging European Parliament election candidates to commit to prioritise dementia in policy.

Vital to this campaign are the voices of people affected by dementia. Videos in the native languages of members from the European Working Group of People with Dementia and European Dementia Carers Working Group were shared, underscoring the urgency of the campaign and encouraging public participation in the Call to Action.
Federazione Alzheimer Italia (FAI) supported the campaign by launching a communication strategy #AlzheimerChiamaEuropa "AlzheimerCallsEurope" on International Women's Day. This kicked-off with a video testimonial of a carer and a dedicated webpage (https://alzheimerchiamaeuropa.it/). The webpage and the communication materials are now disseminated through a press office activity, an email marketing strategy and a social advertising campaign on Facebook and Instagram.
Communications about the public Call to Action led people to an online form on Alzheimer

Europe's website, accessible in 33 languages and automatically adapting to the user's browser language settings (if available).
FAI supported the broader goals of the European dementia movement and enhanced their visibility in Italy. The Call to Action has already 5,071 signatures, with 3,258 from Italy alone.
This presentation will provide an overview of the campaign's reach and impact, focussing on the public Call to Action and the importance of involving people affected by dementia (one of which will also present) in campaigning activities for policy change.

Policy - Campaigning for change

P39. Campaigning for change

P39-03Empowering people with lived experience to shape the future of long-term care: insights from the Commission

Vicki Cahill
Alzheimer Scotland

Through our ongoing engagement with people with lived experience, Alzheimer Scotland recognises that current options for the long-term care of people with dementia are not always designed to meet their complex and specific needs. Our Commission on the future of long-term care was established to identify innovative and cost-effective solutions for achieving any recommended changes to the current model of provision and to consider alternative approaches to delivering more effective long-term care and support. Nonetheless, we recognise the value of engaging the public to better understand their needs and preferences and to shape policies and strategies to address existing challenges in an inclusive, sustainable way. This presentation delves into the pivotal role of public engagement in informing the Commission's work to consider alternative approaches to care and support that will meet the needs of those who need it, in a way that they want to access and receive it. The presentation outlines the process and methods used to engage people with lived experience throughout the work of the Commission, reflecting on the challenges and opportunities encountered in engaging the public effectively in discussions about long-term care. It also summarises the key findings and insights from our public engagement activities. It discusses emerging themes, priorities and concerns voiced by stakeholders informing the Commission's recommendations for policy reform and system redesign.

Policy - Campaigning for change

P39. Campaigning for change

P39-04DEMOTIC (Dementia topics cartoon)

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Dementia is a particular condition which in its symptomatic expressions involves a very broad system, which concerns not only the person living with dementia himself but also the entire family, loved ones as well as all the "care" staff that comes with it. Dementia enters in a disruptive way, altering balances and dynamics with important repercussions on the quality of life of all those involved. This is why we want to try to offer content on the topic accessible to all ages.
We raise awareness and bring as much of the population closer to the topic of aging and dementia through a cartoon helped by the same people living with dementia who are the protagonist voices of the characters.
Method: Involvement of people living with mild dementia in Italian meeting centers in the writing of scripts and in the voice recording of dialogues. Creation of 2 cartoons by a graphic studio. Diffusion of cartoons through the partnership of Scientific Societies and the media. Study on the impact of the cartoon after one year by the Psychology faculty of the University of Bologna.
Expected results: By 2024 production of 2 episodes of the cartoon and initial distribution in the national territory through national scientific societies and the media. Greater awareness on the topic of the elderly person living with dementia and on the possible situations related to it. Data on the impact of cartoons by 2025.

Plenary 3. Innovation in dementia care

P40. Remote/mobile care

P40-01First dental homecare system in Switzerland

Stephanie Casparis, Stephanie Casparis
SimplySmile GmbH

SimplySmile is the first dental homecare system in Switzerland. At SimplySmile we offer a mobile care solution which tackles the problem of lack of accessibility to dental care for the elderly population with different diseases. In a first step, dental care (e.g. regular control) is conducted by dental hygienists who visit the elderly at their place of residence. She is the link between all stakeholders (patient, nursing personnel, physicians, relatives, dentists) and refers to a dentist when further treatments are needed. The dental hygienist is confidant and specialist at the same time. The treatments are accepted as «effective and economically reasonable» care and therefore it`s also accepted by Swiss additional services. So far we are responsible for 120 elderly homes with great success. Our main goal is to reduce bacterial infections through regular cleaning- and desinfection-treatments and consequently keep our patients away from pain and toothloss.

P40. Alzheimer Switzerland - remote/mobile care

P40. Remote/mobile care

P40-02Telemedicine for elderly: patient and clinician experiences in remote cognitive assessment

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Background: With an aging population, cognitive impairments, and dementia present significant challenges. Accurate diagnosis and treatment are essential, yet access to specialized dementia screening clinics is often limited, particularly in rural and isolated areas. Telemedicine offers a promising solution, providing accessible cognitive testing opportunities. This pilot study explores the subjective experiences of elderly patients, focusing on their perceptions and feelings towards digital technology, particularly in remote cognitive assessments as a patient-centered dementia screening method.

Methods: The ongoing pilot study employs telemedicine for remote cognitive assessment conducted via videoconferencing. The videoconference system is specifically designed to perform a full range of neuropsychological tests, supporting early detection of cognitive decline, and monitoring cognitive performance. Data will be analyzed for acceptability and user experience, with a focus on subjective perceptions from the patients' and clinicians' side of remote memory clinic settings.
Results: Expected by October 2024, the study results will highlight both patients' and clinicians' perceptions and experiences of remote cognitive assessments. The analysis will assess the usability of remote assessment and provide deeper insights into telemedicine experiences from both perspectives.
Conclusion: Demonstrating feasibility, this system aims to be permanently established in the canton of Bern, with plans to extend to other German-speaking parts of Switzerland. Ensuring the availability, accessibility, and acceptability of healthcare services is crucial in rural health service delivery. Limited specialized access to memory clinics hinders timely diagnosis and appropriate disease management. This study examines remote cognitive assessment from both patients' and clinicians' perspectives, incorporating their experiences into digital development.

P40. Alzheimer Switzerland - remote/mobile care

P40. Remote/mobile care

P40-03Remote technologies in early stages of Alzheimer's disease: feasibility, usability and acceptance of an app-based cognitive training

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Background: Treatment options for dementia due to Alzheimer's disease (AD) are limited, one recommended intervention is cognitive stimulation. We aim to extend an existing tablet-based cognitive training (CT) programme and assess the feasibility, usability, and acceptance in the home- and care home-setting.
Method: In this non-randomized, observational study 36 participants aged 70-95 are assigned to one of three study groups based on cognitive status assessed at baseline (12 healthy controls (HC), 12 mild cognitive impairment (MCI), and 12 AD). Participants engage in two focus group sessions, one before and one after a 2-week CT programme (10

daily 30-minute sessions conducted either at home or in a care-home setting) and are accompanied by a study partner. In the first focus group session participants and study partners (3-4 participants) are familiarized with the CT programme. Feasibility, acceptability, and usability are evaluated with half-structured group interviews during the focus groups as well as with in-app questions during the 2-week CT. We assess (1) feasibility (sessions completed, levels achieved, drop-outs), (2) usability (time until accomplishment of the first level (learning time), number of times the help button is used), and (3) acceptability (evaluation of the games). Furthermore, we assess feedback from study partners and the extent of support needed during the CT programme, differences between the home and the care home setting, and the influence on mood and wellbeing. The CT app will be continuously optimised based on participants' feedback, starting with HC, followed by MCI and then AD groups.
Result: First results are expected to be disseminated in 2025.
Conclusion: This study addresses a need for remote cognitive interventions with high feasibility, usability and acceptability for people with MCI and AD. The outcome of this study lays the groundwork for future controlled trials to assess efficacy.
This project is supported by Alzheimer Schweiz.

P40. Alzheimer Switzerland - remote/mobile care

P40. Remote/mobile care

P40-04alzguide.ch – Centralized access to support services in Switzerland

Andreina Ravani
Alzheimer Schweiz

Introduction: Adequate services are essential for individuals with dementia and their family caregivers. However, the multitude of available services can be overwhelming, making it increasingly difficult to identify appropriate support.

Method: Alzheimer Switzerland, in collaboration with family caregivers, dementia care professionals, and its cantonal sections, developed the online platform alzguide.ch. This platform offers a centralized access point for dementia-specific services. With a user-friendly filtering function, suitable services can be quickly located by entering the postal code and searching within relevant categories. Services are directly managed by the providers.

Results: alzguide.ch provides a comprehensive overview of more than 650 services, including assessments, consultations, activities for patients, and respite services for family caregivers. The platform is continuously expanded and improved to meet the needs of its users.

Conclusion: The online platform delivers value to both service providers and those affected by dementia. Providers can effectively promote their services, while users gain easier access to high-quality support services.

P40. Alzheimer Switzerland - remote/mobile care

P40. Remote/mobile care

P40-05Patients' and family caregivers' experience with Alzheimer's: a qualitative study and the DIPEx online platform for public dissemination

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Introduction: Many people use social media and the Internet to share their experiences with illnesses and therapies. However, without quality standards, such health information can be ethically and scientifically questionable. DIPEx (Database of Individual Patient Experiences) collects and analyzes patient experiences with various illnesses using an established scientific method (Ziebland and Herxheimer 2008), making them publicly available. The aim is to promote healthcare through peer advice and patient-centeredness. DIPEx is part of a Switzerland-wide healthcare network and a member of DIPEx International (www.dipexinternational.org).

Method: For the DIPEx dementia research project funded by Alzheimer Switzerland, narrative interviews were conducted across Switzerland. These interviews were audio and/or video recorded, transcribed, and qualitatively analyzed, depending on the respondents' wishes and consent. A total of 32 interviews were carried out: 21 with patients' caregivers and 11 with people with dementia. The sample does not include cases of severe dementia; advanced stages are accessed through caregivers' experiences.

Results: The study results are available online (www.dipex.ch/en/module/dementia). For people with dementia, staying active and focusing on the present moment are key strategies. Conversely, caregivers show complete dedication to their loved ones. Due to this "advocate

role", they seek greater involvement in healthcare services. Their experiences highlight how health professionals can adopt a more patient- and family-centered approach.

Conclusions: The DIPEx platform allows patients and caregivers to share information without barriers, and regardless of time or place. In the sense of self-efficacy, patients demonstrate to each other which attitudes and actions can help them live with dementia. Caregivers are supported in decision-making, enabling them to better assess the illness's progression and anticipate future challenges. However, the study also highlights the limitations of online advice, emphasizing the importance of direct contact with health professionals for dementia detection, therapeutic consultations, and the demanding long-term care.

Patient pathways - End-of-life care

P41. End-of-life care

P41-01Efficacy of IPOS-dem and person profiling in Swiss nursing homes: results from a 15-month stepped-wedge cluster randomised trial

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Background: Person centred outcome measures on their own may not be sufficient to change care processes and impact patient outcomes. With the Integrated Palliative Outcome Scale for People with Dementia (IPOS-Dem) an instrument that captures symptom and concerns in people with dementia specific to the long-term care context has been developed. However, an accompanying intervention to improve people with dementia's outcomes, help frontline staff and family members to face and manage the symptoms and concerns of people with dementia has not been described.
Methods: We conducted a 15 month cluster-randomised stepped-wedge trial of a person profiling intervention engaging with frontline staff and their family members. Our primary outcome was quality of life. The intervention effect was estimated using linear mixed models.
Results: 23 nursing homes and 240 people with dementia participated in our trial. We

identified a significant intervention effect on quality of life ($p < 0.001$).
Discussion: Allocating time to repeatedly discuss the care plan and person-centred outcomes of people with dementia improves the quality of life in people with advanced dementia living in long-term care facilities. Starting from a palliative care perspective to develop care plans helps the frontline staff to deliver person-centred care processess. Future iterations of the intervention will seek to increase family participation, which is anticipated to yield even greater improvements in patient outcomes.

Patient pathways - End-of-life care

P41. End-of-life care

P41-02Advance care plans for people living with dementia and their caregivers

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Hospice Isle of Man

Background: Dementia is a palliative care condition (van der Steen et al, 2020). Importance of having conversations about Advance Care Plans (ACP) whilst the person living with dementia (PLWD) is still able to make these important decisions.
Aims: Support caregivers and PLWD with ACP's, reduce unnecessary hospital admissions, improve outcomes related to preferred place of care and death and reduce carer stress and complicated grief outcomes.
Methods: ACP introduced in one to one support sessions with caregivers and in bespoke caregiver training sessions. Quality Improvement Programme (QIP) with Speech and Language Therapist (SaLT) to cover ACP in eating and drinking at all stages of dementia.
Results: Case studies – when it goes wrong / when it works well; Numbers of ACP recorded; Number of places of care / death recorded; QIP results. Forward planning reduces carer stress and allows PLWD to achieve a good death in a place of their choosing. “I feel supported by my Admiral Nurse even though my loved ones have died”. “When my husband was dying it was thanks to the conversations I had previously with my Admiral Nurse that I was calm and in control”. "You supported us and went beyond to give us peace in a difficult time" “You gave me and my family all the information we needed to prepare for [name] dying".
Impact going forward: Eating and drinking training programme for local nursing homes (2024), Moving Forward programme for carers to fill the caring void post bereavement (2024), training to support other professionals to have ACP conversations earlier in the

disease trajectory and building ACP into a dementia pathway / strategy.
Limitations: Small sample sizes, relies on Admiral Nurse to start conversations about ACP and limited window of opportunity to discuss ACP before PLWD loses capacity.

Patient pathways - End-of-life care

P41. End-of-life care

P41-03How to organize advance care planning in young-onset dementia: a scoping review in young and middle-aged adults with serious and chronic illnesses

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Background: Advance care planning (ACP) in dementia may be a desirable process for discussing preferences regarding future care. Extensive studies have been conducted on ACP in older patients with dementia, yet there is little knowledge regarding ACP in people with young-onset dementia (YOD). Patients with YOD may have different needs and preferences. Insights can be gained from applying ACP to other serious and chronic illnesses. The objective of this review is to evaluate the process of ACP in young and middle-aged individuals with serious and chronic illnesses to ascertain its applicability in patients with YOD.
Methods: A systematic search was conducted in PubMed, EMBASE, and CINAHL for qualitative and quantitative studies. The search covered the concepts: ‘advance care planning’, ‘population’, and ‘diseases. One screener conducted title/abstract-screening using AS Review, and two screeners independently performed the full-text screening. The data will be extracted according to the following themes: "How ACP is applied," "When ACP is applied," "By whom ACP is applied," and "Which topics are discussed."
Preliminary results: The search yielded 1.691 unique abstracts, of which 227 relevant full texts. ACP was performed in varied population with various illnesses, including dementia,

cancer, heart failure. Different interventions are available for the discussion of ACP. The optimal timing for initiating ACP should be immediately following diagnosis, although it was recognized that patients should be afforded sufficient time to process the diagnosis. It is recommended that a physician should be responsible for initiating ACP. The desired topics of ACP can be divided into two categories: medical topics (e.g., euthanasia, home care) and non-medical topics (e.g., financial wills, religious and spiritual topics).
Discussion/conclusion: ACP in young and middle-aged people with serious and chronic illnesses can be applied in YOD. However, ACP should be applied earlier in YOD, as cognitive decline affects future decision-making capacity.

Patient pathways - End-of-life care

P41. End-of-life care

P41-04Unveiling perspectives: understanding the meaning of a good death for people living with parkinson's disease

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Background: Parkinson's disease (PD) is the second most prevalent neurodegenerative condition globally. It is characterized by progressive motor and non-motor symptoms, and an increased risk of dementia. The provision of palliative care to People Living with PD (PLwPD) often occurs late or is nonexistent. Despite the growing recognition of the relevance of palliative care for PLwPD, to date, no studies have been found that aim to identify, from the perspective of PLwPD, what constitutes a good death, which is one of the crucial goals of palliative care. This study aimed to give voice to PLwPD regarding this subject through a qualitative approach.
Methods: A convenience sample of 29 PLwPD from the Southeast of Brazil took part in semi-structured interviews between May 2021 and December 2022. A team of interdisciplinary researchers analysed transcripts using inductive thematic analysis.
Results: Our sample of participants was diverse, including PLwPD from various races/ethnicities, genders, ages (range: 36-84 years), religious affiliations, educational backgrounds, and disease stages (Hoehn & Yahr stages 1 to 5). We identified four core themes: "Dealing with fears", "Feeling well-cared for", "Creating opportunities for Joy" and

"Acknowledging spirituality/religiousness". Participants mentioned various fears including both physical and psychosocial issues, such as the fear of becoming completely dependent upon others, experiencing immobility, pain, shame, abandonment, and being a burden to loved ones. Feeling well-cared for related to care at home, feeling valued, being informed, and cared with love and kindness. Opportunities for joy included sensorial and gustatory pleasures, smoking, engaging with hobbies, and being with family. Religiousness/spirituality was evidenced through various desires, including rituals, religious music, transcendental experiences, and believing to have fulfilled their life's purpose.
Interpretation: Our findings expand upon those of previous studies from other populations' perspectives on a good death and enrich the possibilities of person-centred approaches to the care of PLwPD.

Patient pathways - End-of-life care

P41. End-of-life care

P41-05End-of-life interaction between individuals with dementia and their loved ones: incorporation of nonverbal communication and nondeclarative memories

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Literature on how to facilitate end-of-life interaction between individuals with dementia and their families and friends is scanty. The aim of this presentation is to shed light on this critical topic, particularly focusing on individuals with dementia who have severely impaired declarative memory and verbal communication. Based on relevant literature review and his own clinical and academic experience, the author advocates for considering nonverbal communication and nondeclarative memories to facilitate interaction in this context. Relevant strategies to facilitate patients' physical and emotional well-being, and to facilitate family members' acceptance of their loved ones' end-of-life stage and to provide them with opportunities for meaningful communicative moments and closure will be discussed.

Living with dementia - Stigma and discrimination

P42. Stigma and discrimination

P42-02Evaluating the multi-level 'Creating a Dementia Inclusive Generation' programme in Ireland: instilling dementia awareness and combatting stigma in future generations

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Statistics show that one in three young people know someone with dementia (Chirico et al. 2021). The multi-level Creating a Dementia Inclusive Generation programme (The Alzheimer Society of Ireland, ASI) aims to combat dementia stigma and raise awareness among young people. In addition to education, it encourages community participation and students can work towards a Gaisce award (the Irish President's prestigious Award for self-development for young people). Dublin City University evaluated its effectiveness over an academic year.

The evaluation, employing a pragmatic utilisation-focused approach, assessed different implementation methods across schools, including literature review, survey of all programme participants (n=714), focus groups with student participants (n=9) and interviews with coordinators in a subset of schools, and interviews with the programme development team and relevant ASI staff.

Results found that 35.6% of students had at least some experience of dementia; five students had a parent with a diagnosis of dementia. Course satisfaction scores were particularly high (>90%) and 75% of students felt more positive about dementia having completed the programme. Suggestions for future improvements were mixed (e.g. less reading) and sometimes contradictory (e.g. more/less video), highlighting the heterogeneity of the programme audience. Themes developed from qualitative analysis included: Educational Impact (overwhelmingly positive, increased knowledge, shift in perspectives, practical tips to support brain health); Design (higher engagement with interactive materials, quizzes); Implementation (ability to work at own pace, facilitated conversations with peers); and Recommendations for the betterment of the programme.

Such recommendations included increasing personal touch, broadening the interactive elements, the inclusion of a providing a 'take-home' booklet, prescriptive coordinator guidelines, and the facilitation of community links. Considering the fast growth of this programme and the large uptake in recruitment throughout Ireland and abroad, these recommendations provide precise areas of improvement that will support the sustainability and continued growth of this programme.

Living with dementia - Stigma and discrimination

P42. Stigma and discrimination

P42-03Overcoming stigma by engaging youth dementia advocates

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When people engage with people living with dementia, understanding of dementia improves and stigma decreases. When children and youth engage with people living with dementia, there is an opportunity to develop a deep understanding of the lived experience of dementia and a recognition of the ongoing capacity of people living with dementia before stigma of dementia develops. The presenter, a person living with dementia, will discuss her experiences with, and hope for, youth advocacy for dementia. She will describe the engagement of youth through two events, an intergenerational dialogue at a culture change event and a collaborative initiative to co-create a youth dementia advocates toolkit. Preparation for the intergenerational dialogue brought together two people living with dementia, four youths (aged 9 and 10 years), and a researcher over two months, with each participant reflecting on and sharing how youth could support the inclusion of people living with dementia. To develop the youth dementia advocates toolkit, a larger team of people living with dementia, youth, and researchers assembled to develops tools to improve understanding of dementia and promote strategies to support the inclusion and participation of people living with dementia among children and youth. The presenter will reflect on how these intergenerational engagements have influenced the youths' understanding and action related to dementia. She will also share her reflections and hope for youth being part of positive change for people living with dementia.

Living with dementia - Stigma and discrimination

P42. Stigma and discrimination

P42-04Portrayals of living with dementia – through virtual reality: results of a citizen science project



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Background: Many individuals fear developing dementia and hold negative associations with it, which influences their interactions with persons with dementia. We investigated perceptions people hold about dementia, counter-perceptions offered by experiential experts, and if Virtual Reality (VR) can provide more nuanced portrayals.
Methods: We followed the four phases of the Double Diamond model (June 2022-May 2024). Using a photovoice public campaign (N>220) and 3 Structured Interview Matrix sessions (N=48), we explored citizens' perceptions of dementia. Findings were presented to individuals with dementia, informal caregivers, and dementia (social/health)care professionals for supplementary insights and prioritization. A VR film and associated training program were subsequently developed for informal caregivers and (future) health professionals. This prototype VR intervention was evaluated among 6 caregivers, 5 healthcare students, and 4 healthcare professionals through photo-elicitation interviews before and after participating in the training.
Results: Portrayals of living with dementia encompassed: joy of life, dignity and respect, meaningfulness, connection to others, connection to oneself, autonomy, and daily functioning. Coding of comments accompanying submitted images shows that 'joy of life' evokes many negative associations but also offers many opportunities. Many of the negative perceptions are consistent with later stages of dementia. The VR intervention includes scenarios related to joy of life and autonomy. Even though pilot participants already seemed to hold positive portrayals, they became more aware of the impact of their own behaviour and actions on the joy of life and autonomy of individuals with dementia and obtained new insights on how to be more facilitating.
Conclusions: Portrayals seem particularly based on advanced stages of dementia. However, individuals in the social environment of persons with dementia may influence which portrayals become truth, particularly in earlier stages of the disease. A VR intervention can contribute to awareness of portrayals and explicating them, and offer considerations for dementia-friendly approaches.

Living with dementia - Stigma and discrimination

P42. Stigma and discrimination

P42-05Perspectives of people living with dementia and their loved ones on discrimination

Mervi Issakainen, Minni Teerikangas, Katri Gadd, Elisa Tiilikainen, Anna Mäki-Petäjä-Leinonen, Kaijus Ervasti
University of Eastern Finland

In this presentation, we describe our preliminary findings on how discrimination manifests itself in the daily lives of people with dementia in Finland. Discrimination here refers to unfair treatment that can occur in different ways and in different areas of life. Our data consists of writings (n=12) and interviews (n=26) of people living with dementia and their loved ones, as well as their open-ended responses to a questionnaire (n=205). We used theory-guided content analysis to identify both different forms of discrimination and how dementia-related stigma, including stereotypes and prejudice, intertwines with experiences of discrimination. Preliminary results show diminished feelings of belonging: stereotypes and prejudices were described as affecting the opportunities for people living with dementia to be seen as full members of society. The lack of dignity was linked to a discourse that portrays older people and people with dementia mainly as expenses and thus a "burden" for younger generations. People living with dementia were also reported to often face unequal treatment in social relationships and everyday interactions. The experiences most frequently described by participants were related to health and social services, ranging from medical advice on symptoms to round-the-clock care. In addition to the living conditions of people with dementia in general, the participants described the ways in which their discrimination occurred during the Covid-19 pandemic. The results underline the importance of investing in life conditions that ensure the dignified treatment and inclusion of people with dementia. There is a need to improve attitudes in all areas of Finnish society, including services for people living with dementia and their loved ones.

Inclusion and intersectionality - Young onset dementia

P44. Young onset dementia

P44-01Making sense of young onset dementia: a qualitative exploration of childhood experiences

Cathal Blake, Louise Hopper
Dublin City University

Research into young onset dementia (YOD) tends to focus on the experience from the perspective of the person with the condition or that of their primary carer. Many people diagnosed with YOD are part of a wider family system, yet their children's experiences are consistently absent from the literature. This research aims to fill the gap by exploring the often overlooked experiences of children and young adults within families affected by YOD, particularly in Ireland and the broader impact on family dynamics.

Using a qualitative approach, participatory workshops were conducted with members of the Alzheimer Society of Ireland (ASI) Dementia Research Advisory Team (DRAT), which consists of individuals living with YOD. These workshops helped shape the research questions. Additionally, a qualitative systematic literature review was carried out to gather existing knowledge on the experiences of children and young adults with parental YOD. Following this, focus group discussions and semi-structured interviews were held with family members, including individuals with YOD, spouses/partners, and children.

The findings uncovered significant challenges faced by children and young adults due to parental YOD, such as adapting to new circumstances and grappling with heightened emotions like fear, anxiety, anger, guilt, shame, and loneliness. The stigma surrounding dementia, coupled with a lack of awareness and age-appropriate support services, further compounded these difficulties. Many children and young adults refrained from seeking support from peers due to this stigma, which added strain to family dynamics.

In conclusion, children and young adults with a parent affected by YOD require tailored psycho-social support that recognizes their unique challenges. Collaborative interventions involving healthcare providers and affected children are crucial, with peer-to-peer support emerging as a promising strategy. Combining peer support initiatives with education and awareness programs could offer valuable assistance to children and young adults navigating the complexities of parental YOD.

Inclusion and intersectionality - Young onset dementia

P44. Young onset dementia

P44-02European co-creation and implementation of the behavioural program (YOUNG-D) to reduce emotional stress and sleep problems in people with young-onset dementia

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Background: When dementia starts prior to the age of 65 years, the symptoms often progress faster than is the case in late onset dementia (diagnosis >65 years). Young onset dementia (YOD) often goes along with increased stress and sleep problems, which affects heart rate variability and quality of life.
Methods: In 2021, researchers at Odisee University of Applied Sciences (Brussels, Belgium) designed a behavioural program (JONG-D) in co-creation with YOD care providers in Flanders. This program was intended for people with YOD to provide tools and coping mechanisms in Flanders, the regarding stress and sleep management. After a first pilot of this JONG-D program in a semi residential setting in four day care centers, the program was now open for use by European partners. Together with co-funding of the EU Erasmus+ program, researchers from Odisee University of Applied sciences deepened the JONG-D program in co-creation with practical and educational partners in The Netherlands, Denmark and Germany in to an integral YOUNG-D program. In a further stage, the newly designed YOUNG-D program has been implemented in three settings for YOD (residential, semi-residential and outpatient). Out of this co-creation and implementation phase, feedback and experiences of trainers were collected in a YOUNG-D trainers' manual.
Results and conclusions: This European co-creative project resulted in a more tailormade YOUNG-D program to reduce emotional stress and sleep problems in people with YOD. The presentation will provide an insight in perspectives and experiences of trainers and people with YOD in the YOUNG-D program as well as avenues for future research and collaboration. Furthermore, the YOUNG-D program will be made freely accessible to all care providers and researchers in YOD as well as family members of people with YOD.

Inclusion and intersectionality - Young onset dementia

P44. Young onset dementia

P44-03Living is a career, do you know what I mean?: understanding the career experiences of women living with young-onset dementia

Rachel Allen[1], Louise Ritchie[2], Debbie Tolson[2], Emma Bolger[2]
[1], [2]University of the West of Scotland

Career doesn't end with a dementia diagnosis. Though the period following diagnosis can be a difficult time for women living with young-onset dementia, moving through this and continuing career positively is possible. Career is defined broadly as "life and work", focusing on life roles and stages inspired by Donald Super's Life Rainbow (Super, 1980). This understanding of career includes paid work but also other career components such as family and community roles, which have traditionally been gendered. Gendered expectations of women's careers have evolved significantly and now often include a balance of roles inside and outside the home. In this study, women living with young-onset dementia were interviewed online about their career experiences. Object elicitation was used in interviews to facilitate discussions that focused on the experiences and elements of career that mattered to participants. The study explored the intersection of young-onset dementia, career and gender.
This talk will focus on an overview of findings, generated from the interviews and object elicitation, using a reflexive thematic analysis methodology. The role of others post-diagnosis and being able to utilise skills that were developed during employment are examples of enablers for women living with young-onset dementia, helping them to move into a satisfying and encouraging career space following diagnosis. The findings of the research have identified what women have found to be helpful and unhelpful for enabling career continuance, offering important insights for policy and service development to better meet women's needs. Ensuring that women have opportunity and support to connect to others is critical in supporting the careers of women with young-onset dementia, focusing on what is possible rather than what may no longer be practical as dementia symptoms develop.

Inclusion and intersectionality - Young onset dementia

P44. Young onset dementia

P44-04Social care planning and provision for young onset dementia: findings from the DYNAMIC project

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The social care needs of people with young onset dementia and their families are seldom well addressed. Dementia services are associated with ageing and those with young onset can be marginalised. Social care can support independence and autonomy, and facilitate meaningful occupation and relationships. Unmet social care needs are associated with reduced wellbeing and may precipitate crises. There is a great need to improve social care for this group.
In the DYNAMIC study (Dementia at Younger Ages - Mapping Ideal Care) we aim to identify key improvements needed in social care provision for people with young onset dementia and their families and co-produce recommendations and resources to enable these improvements.
In this paper we will present findings from the first half of DYNAMIC on:

- experiences of social care reported by people living with young onset dementia and family supporters
- current practice, knowledge and confidence of staff with a role in social care planning or provision for people with young onset dementia.

Information has been gathered from 25 people with young onset dementia and/or family/friend carers via qualitative interviews and from over 100 social care staff across England via an on-line survey.
Data analysis is in progress and will be completed over Summer 2024. A powerful emergent theme from interviewing people with young onset dementia and their families suggests more guidance or assistance is needed to help this group navigate, make decisions about and access social care support. Early survey findings suggest referrals for social care are reactive rather than proactive, being prompted in response to transitions in needs; that referrals are more commonly triggered by carers' needs rather than those of the individual diagnosed; and that social care staff need significantly greater awareness of the specific challenges faced by people living with young onset dementia and their families.

Inclusion and intersectionality - Young onset dementia

P44. Young onset dementia

P44-05Guidance for life, work and career: the experience of co-producing a career guidance approach to support people living with dementia

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People living with dementia, particularly young onset dementia, often report issues with employment. While research has identified that people with dementia can continue working post diagnosis, it is widely recognised that many people have negative employment experiences. There is an urgent need to develop supports that can respond to the needs of people who are diagnosed with dementia whilst in employment. Career guidance could play a key role in developing person-centred coping strategies and workplace adjustments, as well as supporting employment-related decisions, including around leaving work and finding alternative roles, such as volunteering or joining advocacy groups, like the Scottish Dementia Working Group. This presentation draws on research which co-produced and field-tested a career guidance approach for people living with dementia.
In this co-produced presentation, we reflect on our experiences as a co-production group alongside presenting the findings of our research. Our co-production group membership included six people with a diagnosis of dementia, two family carers, alongside six professionals from a range of disciplines, including two people with expertise in career guidance and four health and social care professionals and two academics. We will discuss our experiences working as a co-production group showcasing the different perspectives of people with lived experience, academics, and practitioners. We will discuss how we addressed power dynamics, learnt from each other, and created a respectful environment that allowed each person to make a meaningful contribution. In doing so, we highlight how being involved in research can be viewed as a form of work for people living with dementia and make recommendations for good practice for co-produced research. We will conclude by showcasing the approach to career guidance that we have developed, and outlining the

potential for career guidance to make a positive difference to the lives of those who are diagnosed with dementia.

P45. eBRAIN-Health

P45. Advancing our understanding of the brain, and developing personalised therapies for dementia and other neurodegenerative diseases

P45-01The eBRAIN-Health project: digital brain twins for discovery & dementia prediction

Leon Stefanovski
Charité University Hospital, Berlin

While our understanding of neuroscience has advanced in recent years, integrating available knowledge, data, and technology remains a challenge. Therefore, the eBrain-Health project aims to revolutionize brain research and healthcare by creating a robust and secure European infrastructure to facilitate the sharing and accessibility of multimodal data across the scientific community.

The development of digital brain twins is the core of this approach — i.e., individually personalized virtual brain models. The Virtual Brain (TVB, thevirtualbrain.org) can generate these digital twins, a neuroinformatics platform developed to simulate brain activity across various scales, from molecular pathways to whole-brain dynamics. By integrating the spectrum from biological and clinical to imaging data, we aim to improve diagnostics and treatments of neurological and psychiatric diseases by simulating disease progression, testing potential treatments in silico, predicting clinical outcomes, and even supporting clinical trials in a virtual testing environment.

This innovation potential could ultimately accelerate the development of personalized medicine. This infrastructure aims to enhance our understanding of the human brain and set new standards for data sharing, collaboration, and innovation in neuroscience, aiming for leadership in digital health and brain research.

P45. eBRAIN-Health

P45. Advancing our understanding of the brain, and developing personalised therapies for dementia and other neurodegenerative diseases

P45-02Data curation as an enabler for efficient sharing of research data for discoverability and reuse

Eszter Agnes Papp
University of Oslo

Building a better understanding of neurodegenerative diseases represents a complex challenge that requires researchers from multiple areas of neuroscience to combine data describing different aspects of the brain in health and disease. Such collaborative efforts depend on the availability of well-annotated research data that are findable, accessible, interoperable, and reusable.

We will present the EBRAINS data curation workflow that aims to prepare the best possible metadata representation of neuroscience data for discoverability and reuse. The workflow involves steps to organize data according to the BIDS standard, and describe each dataset using standardized terms for e.g. acquisition methods, processing steps, subject information, brain regions involved, and data formats in compliance with the openMINDS metadata framework (RRID:SCR_023173). The resulting metadata representation makes it possible to publish and search for the data in the context of other available research data and experimental or computational methods via the EBRAINS Knowledge Graph.

Special considerations are taken to safeguard sensitive human data and metadata. We will demonstrate the data curation process with examples from the eBRAIN-Health project.

P45. eBRAIN-Health

P45. Advancing our understanding of the brain, and developing personalised therapies for dementia and other neurodegenerative diseases

P45-03eBRAIN-health and its federated nodes - synergies and virtual opportunities for personalized neurological medicine

Ira Haraldsen
University of Oslo

The eBRAIN-Health project, funded by Horizon Europe, is developing a distributed medical research platform that models and simulates complex neurobiological phenomena. This project integrates data from various sources such as PET and MRI scans, EEG tests, clinical variables, and behavioural studies, combining clinical data and biological information. This data is used to create digital "brain twins," enabling innovative research. This platform facilitates secure collaboration across multiple research nodes, including the Norwegian node at Oslo University Hospital and the University of Oslo, without centralizing sensitive information. This integration leads to robust knowledge sharing, efficient resource contributions, and reliable algorithm development, leveraging diverse data sources to improve predictive accuracy and model generalizability.

One example explored in this lecture is the AI-Mind project, which aims to develop AI-based tools for the early diagnosis and risk assessment of dementia. It integrates with the eBRAIN-Health initiative to enhance the use of distributed medical data through federated learning.

For more details, visit the eBRAIN-Health project page: https://www.ebrains.eu/projects/ebrain-health.

P45. eBRAIN-Health

P45. Advancing our understanding of the brain, and developing personalised therapies for dementia and other neurodegenerative diseases

P45-04How are my rights protected? Policy frameworks governing health data in the European Union (European Health Data Space)

Klaudia Kwiatkowska
University of Vienna

In April 2024, the European Union institutions agreed on the final text of the European Health Data Space (EHDS). This law aims to enable individuals to manage their electronic health records and facilitate more effective exchange of health data for the provision of healthcare (primary use of data) within and across Member States. Furthermore, the EHDS aims to provide a harmonized and trustworthy infrastructure for re-using health data for research, innovation and regulatory purposes (secondary use of data). At the same time, the EHDS aims to protect the health data and privacy of individuals.

The aim of the presentation is to outline how the rights of individuals will be protected in the secondary use system envisioned by the EHDS. The presentation will focus on use cases from the eBRAIN-Health project.

P45. eBRAIN-Health

P45. Advancing our understanding of the brain, and developing personalised therapies for dementia and other neurodegenerative diseases

P45-05Lay perceptions of digital brain twins and ethical issues raised in Public Involvement work regarding their potential use in clinical practice

Dianne Gove
Alzheimer Europe

Artificial Intelligence (AI) can help researchers and health practitioners to diagnose, treat and prevent brain diseases, by enabling them to analyse and interpret complex datasets. Researchers are currently developing health data platforms and AI models to predict whether a person is likely to develop dementia. In the future, this could enable early treatment and improved medical care. However, AI and other groundbreaking technologies come with several potential ethical dilemmas. AI models are trained on large amounts of data, including sensitive personal data relating to the health of vulnerable individuals. There are also challenges linked to bias, which may have harmful consequences for underrepresented or marginalised groups. The way that lay people perceive and make sense of digital brain twins is also central to their ethical and trustworthy use in clinical practice. This presentation will explore these issues and present some of the recent Public Involvement work on this topic.

Innovation in care and research - Clinical trial recruitment and retention

P46. Clinical trial recruitment and retention

P46-01Enhancing intervention retention for family caregivers of people with dementia: a meta-analysis on predictors of dropout from online self-help interventions

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Introduction: Online self-help interventions have emerged as a promising and innovative approach for supporting family caregivers of people with dementia. However, dropout rates in these interventions pose a significant challenge to their utility and effectiveness. Understanding the factors influencing dropout is crucial for enhancing intervention adherence and improving caregiver outcomes. A meta-analysis was conducted aiming to identify predictors of dropout from online self-help interventions in family caregivers of people with dementia, providing insights for intervention refinement and future research directions. Methods: A systematic literature search was conducted, resulting in the inclusion of 18 studies involving 1,215 family caregivers. Methodological quality assessment, study selection, and data extraction were performed according to predetermined criteria. Dropout rates and associated predictors were analysed using meta-analytic techniques, considering factors such as intervention characteristics, implementation strategies, and caregiver demographics. Results: The overall dropout rate was found to be 18.4%, with significant variability across studies. Factors associated with lower dropout rates included human contact, interactive features, and personalisation strategies within interventions. Reasons for dropout included perceived intervention unsuitability, changes in care recipient circumstances, and intervention burden. Conclusion: This meta-analysis highlights the need for more detailed reporting on reasons for dropout and emphasizes the importance of inclusive intervention design to address the diverse characteristics of dementia caregiver populations. Methodological limitations suggest a need for future research to prioritise personalisation strategies and human support to enhance engagement in online interventions, particularly for underrepresented caregiver samples. By incorporating these strategies, future interventions can improve effectiveness and support for family caregivers of people with dementia.

Innovation in care and research - Clinical trial recruitment and retention

P46. Clinical trial recruitment and retention

P46-02Recruiting persons with dementia as study participants: a systematic review of facilitators, barriers, and strategies

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Background and objectives: Dementia care researchers seek to develop and evaluate interventions to improve quality of life in persons with dementia. To gain a deeper understanding of their needs and to assess the benefit of dementia-specific interventions, it is essential that persons with dementia take part in research. However, study recruitment of persons with dementia is challenging. We aimed to investigate facilitators and barriers to identifying and approaching persons with dementia for recruitment to dementia care studies and to determine the effectiveness of recruitment strategies. Methods: We performed a systematic review of methodological studies that investigated facilitators and barriers to identifying and approaching persons with dementia for recruitment to dementia care studies and/or determined the effectiveness of recruitment strategies (CRD42022342600). We systematically searched MEDLINE/PubMed, CINAHL, Web of Science, ORRCA (Online Resource for Research in Clinical triAls), and pertinent evidence syntheses and conducted citation searching of all included studies. The results were summarized narratively. Results: We identified 18 studies; half published within the last three years and mostly conducted in the United States or United Kingdom. Facilitators and barriers consisted of “characteristics of participants, researchers, clinical contact persons”, “study characteristics”, and “communication with participants”. To recruit persons with dementia, the included studies assessed information-based strategies, networking and collaboration, study-related aspects, and multimodal strategies. The highest number of participants were recruited by study information in electronic and print formats, as well as by networking and collaboration. Advertisements proved to be the most expensive way of recruitment. Conclusions: There is limited evidence on the effectiveness of recruitment strategies in dementia care studies. Our analysis of facilitators and barriers highlights the situation of participating persons with dementia, researchers, and clinical contact persons. It may inform and guide research teams in designing strategies to identify persons with dementia for recruitment to dementia care studies.

Innovation in care and research - Clinical trial recruitment and retention

P46. Clinical trial recruitment and retention

P46-03Clinical-effectiveness of DREAMS START intervention for people with dementia and sleep disturbance: single masked, parallel arms, superiority randomised controlled trial

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Background: Sleep disturbance is common and distressing for people with dementia, with no known safe, effective treatments. We aimed to establish whether DREAMS-START (Dementia RElAted Manual for Sleep; STrAtegies for RelaTives), a multimodal non-pharmacological intervention is clinically-effective in reducing sleep disturbances in people with dementia at home after 8 months compared to usual care. Methods: We conducted a two-arm, multi-centre, parallel arms, superiority randomised controlled trial with masked outcome assessment, recruiting dyads of people with dementia and sleep disturbance, and their family caregivers, in English community settings. Participants were randomised (1:1) to DREAMS-START or usual treatment. DREAMS-START is a six-session, manualised intervention delivered by supervised, non-clinical graduates. Personalised strategies include increasing routine, comfort, light exposure, relaxation, and activity. Outcomes were collected at baseline, 4 months, and 8 months. The primary outcome was Sleep Disorders Inventory (SDI) score at 8 months. Analyses were intention to treat. Secondary outcomes for people with dementia included quality of life, daytime sleepiness, and neuropsychiatric symptoms and for family caregivers - quality of life, sleep disturbance, mood, and burden. Results: Between February 2021 and March 2023, 377 participant dyads were randomised, 189 were allocated to usual treatment and 188 to intervention. Mean SDI score at 8 months was lower in the intervention arm versus usual treatment (15.16 [SD 12.77], n=159, vs 20.34 [16.67], n=163]; adjusted difference in means -4.70 (95% CI -7.65 to -1.74; p=0.002). At 8 months carer sleep (difference in means 0.57 [95% CI 0.10 to 1.05]) and carer anxiety (difference in means -0.86 [95% CI -1.71 to -0.01]), were significantly lower in the intervention group than usual treatment. Conclusion: To our knowledge, this is the first and largest fully powered RCT of a multicomponent non-pharmacological intervention that

improves sleep in people living at home with dementia and their caregivers, with sustained effectiveness beyond delivery.

Innovation in care and research - Clinical trial recruitment and retention

P46. Clinical trial recruitment and retention

P46-04It's a kind of legacy: exploring the acceptability and feasibility of advance research planning to support inclusion of people living with dementia in clinical trials

Victoria Shepherd, Kerenza Hood, Fiona Wood
Cardiff University

Background: Clinical trials involving people living with advanced dementia can be challenging due to the 'proxy consent' arrangements required for participants lacking capacity. In these situations, families often make participation decisions. However, these decisions may not be in accordance with what the person themselves would want. In the UK, existing processes for people to plan ahead for their care should they lose capacity in the future, such as advance care planning, don't include preferences about research. Advance research planning (ARP) may provide an innovative solution. ARP is a process in which people are encouraged to think, discuss and express their preferences about taking part in research. It may include making an advance research directive and choosing who should be involved in decisions. Whilst ARP has been introduced in some countries, it has not previously been explored in the UK. Methods: We conducted a mixed-methods study with researchers, practitioners, and members of the public (including people with dementia and carers) to explore the acceptability and feasibility of introducing ARP and to identify barriers and facilitators. Results: An online survey with 327 stakeholders (members of the public n=277, professionals n=50) found high levels of support (97% of public members, 94% of professionals). They identified a number of challenges, including how ARP could take account of changes in individuals' preferences whilst protecting their rights and interests. Semi-structured interviews with purposively sampled participants (n=27) identified six main themes: 1) opportunities to engage with ARP; 2) using ARP to inform participation decisions; 3) optimising ARP timing; 4) modes for recording preferences; 5) minimising unintended consequences; and 6) ensuring safeguarding and addressing inequalities. Discussion: The findings provide insights to inform the introduction of ARP in the UK.

Facilitative strategies include embedding it in existing care and research pathways. Additional work has explored international experiences of ARP.

Innovation in care and research - Clinical trial recruitment and retention

P46. Clinical trial recruitment and retention

P46-05Moving science forward: perspectives on dementia clinical trials from people living with dementia, informal caregivers and undergraduate medical students

Laura O'Philbin[1], Anne-Marie Miller[2], Diane O'Doherty[1], Iracema Leroi[2]
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Background: The success of clinical trials relies heavily on participant recruitment and retention, which are often challenging in the context of dementia. Misconceptions and mistrust surrounding clinical research further compound these challenges. As advancements in dementia therapies and diagnostics continue, optimising recruitment, retention, and workforce training is essential. Methods: The Alzheimer Society of Ireland of Ireland and Dementia Trials Ireland collaborated to survey people living with dementia, informal caregivers, and undergraduate medical students (UMS) on attitudes and perceptions related to dementia clinical trials through online, telephone and face-to-face surveys. Results: Data from 64 people with dementia, 523 informal caregivers and 58 UMS revealed overwhelming agreement that clinical trials are necessary to progress healthcare (98% people with dementia, 97% caregivers, 100% UMS). 85% of people with dementia and 79% of caregivers would volunteer to participate in dementia clinical trials though there is trepidation, with many agreeing 'with some reservations'. Access to new treatments, moving science forward and helping future generations are key motivators. 83% of UMS would consider health research in their future career; however many deemed their health research (59%) and clinical trial (54%) training to be inadequate or somewhat inadequate with 80% reporting a lack of awareness of current dementia trials. UMS identified improved access to research opportunities (54%); earlier and improved integration of research training into curricula (42%); and more mentorship (40%) central to better engagement. Discussion: It is essential to educate the public on clinical trials and to amplify trusted and balanced sources of information to capitalise on interest while addressing fears and concerns. Students lacking a comprehensive grasp of clinical research practices will struggle to engage with the rapidly

evolving dementia healthcare landscape. Medical curricula must improve the integration of research training and provide supported research opportunities to bridge the gap between theory and practice.

Policy - Dementia strategies

P47. Dementia work force

P47-01From idea to implementation: the creation of the reference doctor on dementia in Flanders (Belgium)

Jurn Verschraegen
Centre of Expertise on Dementia Flanders

The starting signal for the 'Dementia reference doctor training' was given in June 2023. In our talk we describe the way towards the educational package that we have developed. As part of the pilot project reference doctor dementia, the e-learning 'Training for reference doctor dementia' started in October 2023. The Flanders government wanted to install more knowledge about dementia in current and future doctors.

The aim of the training is to provide doctors with tools for early recognition of signs of dementia, making the right (care) diagnosis. The Dementia Plan Flanders 2021-2025 emphasises the role of the GP in early recognition of signs of dementia, diagnosis and care diagnosis, treatment and patient follow-up. In the Dementia Plan Flanders, a dementia reference doctor is a general practitioner, geriatric psychiatrist, geriatrician or neurologist who provides advice to fellow doctors facing questions about patients with dementia.

At the macro level, the dementia reference doctor identifies challenges to policy in consultation with the regional Centres of Expertise on Dementia. At the meso level, we notice an awareness-raising role, working with the first-line zone, local policymakers and care facilities. In doing so, he also has an advisory role to the first-line zone and actively promotes his expertise in dementia. In this talk, we reflect on the way we're developing now our next steps and share our experiences and success factors of the concept.

Policy - Dementia work force

P47. Dementia work force

P47-02Conceptualising and refining the role of Dementia Champions as an opportunity to upskill the homecare workforce

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Background: There is an increasing need for homecare support for people living with dementia. However, poor staff retention rates and various sector challenges have caused a workforce crisis. Homecare workers report having little opportunity for career development. The role of Dementia Champions (DCs) can provide an opportunity for workers to upskill and specialise in dementia care, although little attention has been given to the role in homecare relative to other health and social care settings.
Methods: Across four interlinked work packages, we used innovative methods such as science illustration to engage people living with dementia, family carers, and health and social care professionals. We conceptualised and refined the DC role with support from key stakeholders, and used a Theory of Change framework to underpin the key mechanisms of action needed to implement, embed, and maintain the role in homecare.
Findings: Lack of managerial support and high workloads were identified as barriers to the role, making opportunities to upskill and take on greater responsibilities feel overwhelming and out of reach for homecare staff. Career development should be encouraged and supported through managerial support and organisational 'buy-in'. Other facilitators to the role included: protected time for DCs to achieve role expectations; opportunities for training and updating knowledge; efforts to provide role recognition; and role clarity. We developed a job description and person specification to support providers and aid visibility of the role.
Conclusion: We found considerable demand amongst the homecare workforce for opportunities to develop and specialise. The DC role presents an opportunity for homecare workers who are passionate and knowledgeable about dementia care to progress, making homecare an attractive and sustainable profession. We will present our findings using creative outputs developed to showcase key messages from this work, including a co-produced illustration of our DC in homecare model, and an animation.

Policy - Dementia work force

P47. Dementia work force

P47-03Scottish Dementia Working Group and National Dementia Carers Action Network - sharing our experience: supporting workforce development

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[1]Alzheimer Scotland, [2]National Dementia Carers Action Network, [3]Scottish Dementia Working Group

Scotland's two member-led national active voice groups, the Scottish Dementia Working Group (SDWG) and the National Dementia Carers Action Network (NDCAN), are made-up of people with a diagnosis of dementia, carers, and former carers of people with dementia. The Groups campaign for the rights of people with dementia and carers to influence policy and practice at all levels.

Members from both Groups decide their own priorities and focus areas, informed by personal experiences. Their current commitments include a priority to support workforce knowledge and development, ensuring that all health and social care staff working with people living with dementia, their families and carers have opportunities to achieve appropriate knowledge and skills in their roles, informed by people with personal experience.

Group members regularly participate in development sessions with existing and future workforce, sharing their experience to inform policy and practice. In recent months sessions have included:

- offering carers' perspectives at a dementia training session with Health Care Assistants in NHS Lothian, which delivers healthcare to the second largest residential population in Scotland
- providing insightful personal narratives to a Scotland-wide Allied Health Professionals (AHPs)
- learning event on the theme of a 'Human-Rights Based Approach to Rehabilitation for People Living with Dementia'
- sharing personal experiences at various learning events across Scotland, including with Speech and Language Therapy Students; Social Care Students; and first- and second-year Junior Doctors - providing them with insights that they will carry forward as they progress into their new careers
- contributing to the development of NHS Education for Scotland's 'new to skilled' dementia training programme for the health and social care workforce across Scotland

The positive feedback the Groups received from these events highlights the importance and value of the contribution of those with personal experience to informing and supporting workforce development.

Policy - Dementia work force

P47. Dementia work force

P47-04Dementia education for Diagnostic Radiographer's students: impact on confidence, knowledge, and attitudes towards dementia

Ana Barbosa, Ciara McNally, Clare Mason, Danielle Jones, Erin Berry
University of Bradford

Background: Health care professionals working with people with dementia require necessary confidence, knowledge, and attitudes to deliver person-centred dementia care.
Despite their frequent contact with people with dementia and their crucial role in diagnosing the condition, radiographers receive limited education on dementia during their degree programmes. People with dementia report feeling dissatisfied with the radiology services.
To address this, a bespoke dementia education, including an awareness session on dementia and clinical simulation, was co-designed with people with dementia and caregivers.
Aim: This presentation aims to share the impact of the education package on diagnostic radiography students' confidence, knowledge, and attitudes towards dementia. Additionally, it will provide insights into the process of co-designing education with people with dementia and caregivers.
Method: Thirty undergraduate diagnostic radiography students at a UK Higher Education Institution (HEI) completed the education package. A survey including the Confidence in Dementia Scale (CDS), Dementia Knowledge Assessment Tool (DKAT2), Dementia Attitudes Scale (DAS), and open-ended questions, was used before and after the delivery of the education package. The Wilcoxon signed-rank test was used to analyse pre-post changes on CODE, DKAT2 and DAS and thematic analysis were used to analyse qualitative data. Ethics approval was obtained from the HEI.
Results: The educational package was rated positively by students. The simulation was particularly appreciated given the opportunity to interact with people with dementia and receive immediate feedback about practice. Results suggest improved attitudes towards dementia and significant improvements in students' confidence and knowledge.
Conclusion: This project highlights the benefits of dementia education for radiography students. The bespoke education package showed potential to enhance students' understanding and preparedness to care for people with dementia. The study contributes to the growing evidence on the effective co-design of education and could help address the dissatisfaction that people with dementia often feel towards radiology services.

Policy - Dementia work force

P47. Dementia work force

P47-05Dementia content and delivery in physiotherapy curricula: an international study of entry level physiotherapy programs in Ireland, the United Kingdom and New Zealand

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Background: Physical impairments associated with dementia include reduced gait speed, reduced muscle strength and diminished postural control, all of which can lead to an increase in falls and hip fractures. Physiotherapy can play a key role in many aspects of dementia care, including strength training, falls risk prevention, discharge planning and end of life care. However, there is a lack of dementia education in entry level physiotherapy programs.
Aim: The aim of this study was to map the dementia content and delivery in the current undergraduate and entry level physiotherapy curricula in Ireland, the United Kingdom and New Zealand.
Design: This cross-sectional survey-based study was distributed via the online survey tool Qualtrics XM. The survey was designed using Kern's curriculum design framework.
Participants: The academic leads for dementia education in the identified higher educational institutes were invited to participate in the study.
Data Analysis: A descriptive analysis of independent variables was undertaken. Free text comments were analyzed using summative content analysis.
Results: Of the 69 eligible higher educational institutes contacted, 49 responded, giving a response rate of 71%. Different sources informed curriculum design, including patient and public involvement, published guidelines and policies and expert clinicians. The time allocated to dementia teaching across the curricula varied, with almost half of the programs only allocating two hours teaching. Some novel and innovative approaches were reported including case simulation and the application of an integrated curriculum. The lack of service user input was seen as a perceived weakness of many programs as was the non-standardization and generalized nature of teaching.

Conclusion: Our findings have the potential to inform the design, content and delivery of dementia education at entry level physiotherapy programs. Dementia educational content needs to align with the learning needs of physiotherapists working in dementia care.

P48. Alzheimer Switzerland - Dementia sensible community

P48. Demensensible Gesellschaft – Beiträge von Alzheimer Schweiz

P48-01FREIRAUM - Begleitete und ressourcenorientierte Freizeitaktivitäten für Menschen mit einer Demenz

Natalie Hamela
Alzheimer Bern

Mit dem Freizeitangebot FREIRAUM bietet Alzheimer Bern Menschen, die von einer Demenz betroffen sind, regelmässige begleitete und ressourcenorientierte Aktivitäten ausserhalb des Alltags. Gleichzeitig können betreuende Angehörige den freien Nachmittag für eigene Bedürfnisse nutzen.
Alle zwei Wochen treffen sich die Gäste im Berner Generationenhaus, im Herzen von Bern. Im öffentlichen Gebäude mit Innenhof begegnen sich Mütter mit Kindern, Studierende und Senioren. Der FREIRAUM liegt in einem freundlichen Raum im Erdgeschoss, so dass die Gäste beim Kommen und Gehen Teil des sozialen Erlebens sind und bei verschlossener Tür doch unter sich.
Eine erfahrene Aktivierungsfachperson sowie geschulte, einfühlsame Begleitpersonen bilden den personellen Rahmen und geben den Gästen das Gefühl des Angenommenseins. «Hier kann ich so sein, wie ich bin» so eine alleinlebende Dame, die ein paar Jahre zu Gast war.
Vier Themennachmittage wechseln sich das ganze Jahr über ab: Bewegung, Musik, Kreativität und Spiele. Je nach Thema, Tagesform und Ressourcen der Gäste entstehen Aktivitäten, die sie zum Lachen, Singen oder in Bewegung bringen. Es wird auch mal etwas kreiert, wie selbst gemachte Konfi oder gemalte Bilder, die sie als Geschenk mit nach Hause nehmen, womit auch das Gefühl der Selbstwirksamkeit gestärkt wird.
Ein wichtiger Bestandteil ist auch der Austausch zu Beginn und am Ende des Nachmittags. Dieser findet oft auf spielerische Art statt, zum Beispiel mit Unterstützung eines grossen Bilder-Würfels. Als musikalischer Rahmen startet und endet der FREIRAUM immer mit dem gleichen Lied, das alle gut kennen und gerne singen, ein wichtiges Element, um Sicherheit zu geben.
Der FREIRAUM ist keine Therapie, sondern es ist ein Zusammenkommen auf Augenhöhe,

welches zum Ziel hat, die eng gewordene Komfortzone des Alltags durch positive Erlebnisse zu erweitern und das Person-sein zu stärken.
Der Lohn für die Angehörigen ist neben ihrem freien Nachmittag auch das Lächeln, das sie von ihrem aufgestelltenPartner bekommen, wenn sie diesen wieder abholen.

P48. Alzheimer Switzerland - Dementia sensible community

P48. Demensensible Gesellschaft – Beiträge von Alzheimer Schweiz

P48-02Schulung Bankpersonal, Einsatz Demenzsimulator Hands-on Dementia

Edith Kaufmann
Alzheimer Luzern

Neben den Gesprächsgruppen und den Café TrotzDem gehören Informationen und Schulungen über Demenz zu den Hauptangeboten von Alzheimer Luzern.

In Zusammenarbeit mit der Leiterin Ausbildung einer Bank mit 1300 Mitarbeitenden wurde eine Schulungseinheit für Kundenberaterinnen und -berater konzipiert und mehrmals durchgeführt.

Die halbtägige Schulung besteht aus vier Teilen:

1. Das Krankheitsbild, die Diagnose, die Symptome, Behandlungsmöglichkeiten und Auswirkungen für die Betroffenen, ihre Angehörigen sowie Dienstleister (Pflegefachperson HF von Alzheimer Luzern).

2. Demenzsimulator Hands-on Dementia: Die Kursteilnehmenden erleben in alltäglichen Situationen, wie sich die Symptome einer Demenz anfühlen können.

3. Eine Mitarbeiterin vom Rechtsdienst der Bank (Juristin) behandelt die Themen Urteilsunfähigkeit, Vorsorge, Rechte und Pflichte des Personals, Beobachtungen und die Sorgfaltspflicht.

4. Fallbeispiele werden in der Gruppe analysiert und Lösungsmöglichkeiten entwickelt.

In der Präsentation werden die Schulungsinhalte detaillierter erläutert und eine Zusammenfassung der Rückmeldungen der Teilnehmenden präsentiert.

Alzheimer Luzern trägt mit dieser Zusammenarbeit zu einer dementia sensiblen community bei.

P48. Alzheimer Switzerland - Dementia sensible community

P48. Demensensible Gesellschaft – Beiträge von Alzheimer Schweiz

P48-03«Best Practice»-Projekt Koordinationsstelle «Demenz leben» Kanton Solothurn

Nadia Leuenberger
Alzheimer Solothurn

Im Auftrag des Kantons Solothurn betreibt Alzheimer Solothurn die Koordinationsstelle «Demenz leben», eine physische Anlaufstelle und die Website demenzleben-so.ch, auf welcher alle Demenzangebote im Kanton Solothurn registriert sind, und auf welcher umfassende, aktuelle und verlässliche Informationen über Alzheimer und Demenz im Kanton Solothurn der breiten Öffentlichkeit zugänglich gemacht werden. Die Koordinationsstelle hat zum Ziel, Betroffene, Angehörige, Pflegekräfte und Interessierte mit den notwendigen Ressourcen und Wissen zu versorgen, damit diese den herausforderungsreichen Alltag mit Demenz besser bewältigen können.

Mit dem Betrieb der Koordinationsstelle sowie der Website hat Alzheimer Solothurn im Auftrag des Kantons Solothurn zwei prioritäre Massnahmen aus der kantonalen Demenzstrategie umgesetzt. Die Koordinationsstelle besitzt Pioniercharakter; «Demenz leben» ist die erste Koordinationsstelle für Demenz in der Schweiz.

In der Präsentation wird die Koordinationsstelle und ihr Angebot als «Best Practice» Beispiel vorgestellt.

P48. Alzheimer Switzerland - Dementia sensible community

P48. Demensensible Gesellschaft – Beiträge von Alzheimer Schweiz

P48-04Soziale Teilhabe, Inklusion und Freude durch Musik und Tanz für Menschen mit und ohne Demenz

Muriel Meyer[1], Nina Wolf[2]
[1]Alzheimer Zürich, [2]

Wir beleuchten drei innovative und inklusive kulturelle Initiativen, die Menschen mit und ohne Demenz zusammenbringen und durch Musik und Tanz Freude fördern. Die drei Veranstaltungen bieten niederschwellige und kostenlose Unterhaltungsmöglichkeiten, die auch als Plattform für soziale Integration und Stigmabewältigung dienen.

Tanzmatinée im Zürcher Hauptbahnhof: Dank der Unterstützung des Migros Kulturprozents, konnte die Bühne des Sommernachtsballs am Sonntagmorgen für eine Tanzmatinée genutzt werden. Ein passionierter DJ legte Vinyl mit tanzbaren Songs für Klein und Gross auf, die Gäste wie auch spontan Durchreisende zum Tanzen animierten. Das Schweizerische Rote Kreuz Kanton Zürich stellte zudem einen Begleitservice für Menschen, die Unterstützung bei der An- und Abreise benötigten, bereit. Eine wertvolle Plattform also für Menschen mit und ohne Demenz mit Freude an Musik und Tanz. Das Schöne: auf der Bühne zeigt sich in keiner Weise, wer demenziell erkrankt ist und wer nicht und der Anlass zeugt auch von gelungener Kooperation zwischen Partnern aus Wirtschaft, Kultur und Soziales.

Weischno-Chor: Der Weischno-Chor probt einmal wöchentlich und richtet sich an Menschen mit und ohne Demenz. Durch das gemeinsame Singen bekannter Melodien und Evergreens aus verschiedenen Stilrichtungen werden Erinnerungen geweckt und das Gemeinschaftsgefühl gestärkt. Die Lieder werden in entspannter Atmosphäre einstudiert und das aktive Musizieren fördert Geist, Wohlbefinden, soziale Teilhabe und Interaktion.

riCORdi-Mitsingkonzerte: Diese werden Speziell für die italienisch sprechende Community angeboten. Unter der Leitung einer Musiktherapeutin werden traditionelle italienische Volkslieder gesungen und musikalisch begleitet, um Kindheitserinnerungen zu wecken und ein Stück „Italianità“

nach Zürich zu bringen. Die Konzerte sind ohne Anmeldung zugänglich und nach dem musikalischen Aktivsein sind alle zu einem gemütlichen Aperitif eingeladen

Die drei Initiativen zeigen, wie durch Musik, Gesang und Tanz Freude und Unterhaltung geschaffen werden können, während gleichzeitig Inklusion und soziale Teilhabe gefördert werden. Sie bieten einen wertvollen Beitrag zur Entstigmatisierung von Demenz und regen zur Zusammenarbeit mit verschiedenen gesellschaftlichen Partnern an.

P48. Alzheimer Switzerland - Dementia sensible community

P48. Demensensible Gesellschaft – Beiträge von Alzheimer Schweiz

P48-05«Qualitätssicherung der Angebote und Dienstleistungen von Alzheimer Schweiz»

Annette Gfeller
Alzheimer Schweiz

Alzheimer Schweiz und die 21 kantonalen Sektionen bieten für Menschen mit Demenz und deren Angehörigen viele unterschiedliche Dienstleistungen an. Die Vielfalt der Angebote und die Berücksichtigung der Situationen und Bedürfnisse in den Regionen ist eine Stärke des Angebots.
Eine möglichst einheitliche Qualität der Dienstleistungen ist für Alzheimer Schweiz als Gesamtorganisation, die Nutzerinnen und Nutzer der Angebote sowie für den öffentlichen Finanzierer wichtig. Aus diesem Grund wurden in einem partizipativen Ansatz verschiedene Instrumente zur Qualitätssicherung entwickelt.
In der Präsentation werden die verschiedenen Instrumente vorgestellt und über die Erfahrungen mit diesen berichtet.

Plenary 1. Living with dementia

PL1. Two voices, one story – navigating dementia together

PL1-01Dementia and relationships, the changes that may come along the journey

Shelagh Robinson
Alzheimer Europe

A dementia diagnosis inevitably brings changes in relationships. Some people are there for the journey. Others, and sometimes the most unexpected, fall by the wayside. The experience of new friendships with others sharing the lived experience of dementia is invaluable and life-enhancing.

Plenary 1. Living with dementia

PL1. Two voices, one story – navigating dementia together

PL1-02The power of approaching life positively

Liv Thorsen
Alzheimer Europe

What do we focus on when someone we love is diagnosed with dementia? On all the things our loved ones can no longer do, that life will not turn out the way we dreamed it would? Or on the resources and all the things that still work? My experience is that by choosing to focus on what still works, everyday life becomes easier and the quality of life increases. I am primarily Kjell's wife, and not a carer. This has helped us a lot and contributed to 10 years of good quality of life. I will now tell a little about how it has gone.

Plenary 1. Living with dementia

PL1. Two voices, one story – navigating dementia together

PL1-04Keep doing what you are doing for as long as you can

Paddy Crosbie
Alzheimer Europe

One of the most important pieces of advice I was given following Derek's diagnosis was to "keep him doing as much as he can for as long as he can". It turned out to be the best advice I was given that helped me through our dementia journey. It not only benefited Derek but me also, as it was a way of keeping him engaged with his life and allowing me to continue with mine. By sharing this I hope it could help another person on a similar journey.

Plenary 1. Living with dementia

PL1. Two voices, one story – navigating dementia together

PL1-05Independence, hope and courage. Challenges and successes of living with young onset Lewy body dementia. My journey to a self-determined life with dementia

Lieselotte Klotz
Alzheimer Europe

At 57, a successful entrepreneur, I lost most of my social, societal, and professional roles with the diagnosis in 2017. Although I had defined myself as a successful businesswoman, decisive family manager and passionate sailor, what remained at first was only the diagnosis of Lewy Body Dementia. In my talk, I will tell you about my journey with Lewy body dementia, from the first symptoms to impressive successes in everyday life. I hope you will be inspired by my self-determination strategies, crucial diagnostic steps and innovative therapeutic approaches, and will immerse yourself in a story of courage, resilience and joy that emphasises the importance of self-efficacy and social participation.

Plenary 1. Living with dementia

PL1. Two voices, one story – navigating dementia together

PL1-06Humanity comes not from rules but from the heart

Trevor Salomon
Alzheimer Europe

My presentation will illustrate how a caring employer not only gave my wife 4 years of unanticipated post-diagnosis dignity but also, as a result, allowed me an unexpected degree of independence. I used this time to learn more about dementia caring, build a network of male carers, maintain social relationships…….and breathe.

Plenary 2. Making dementia a priority

PL2. Making dementia a priority

PL2-01Dementia in Swiss health care policy

Margit Jochum Christin, Charlotte den Hollander, Lea von Wartburg
Federal Office of Public Health (FOPH)

Swiss health care policy is characterised by federalism, subsidiarity and liberalism: The Confederation, cantons, municipalities and private actors share responsibility for high-quality health care.

To ensure the best possible care and support for people with dementia, their caregivers and the professionals involved, the Federal Office of Public Health, together with the cantons, has implemented the National Dementia Strategy 2014 - 2019. Despite the successes of the strategy, there is still a need for further action to ensure optimal care. After six years, the strategy has therefore been transferred to the current National Dementia Platform. The platform focuses on:

- Developing and updating key documents (including products of the strategy);
- Supporting the dissemination and implementation of these documents in practice;
- Promoting networking among stakeholders.

The presentation will go into more detail about the objectives, structure and activities of the platform.

Plenary 2. Making dementia a priority

PL2. Making dementia a priority

PL2-02Key achievements of the Global action plan on the public health response to dementia

Katrin Seeher
World Health Organization

The adoption of the Global action plan on the public health response to dementia 2017-2025 has allowed for a more systematic approach to improving the lives of people with dementia and their carers, and decreasing the impact of dementia worldwide. Although important progress has been made since the plan's endorsement, the second round of Global Dementia Observatory (GDO) data collection in 2024 indicates that none of the global targets will be achieved by 2025.

This presentation will critically review progress made to reaching global targets and outline key achievements and gaps. Examples of achievements include development of a wide range of normative tools and products across all seven strategic areas of the plan, scientific advances in our understanding of dementia, iSupport (a skills training proram for carers of people with dementia) being implemented in all WHO regions, and increased country participation in routine dementia monitoring efforts. While scientific advances, availability of new tools and resources, and strengthening of networks have helped build confidence and momentum to explore new and better ways to address existing gaps, in this presentation we will discuss how to build on this momentum, it is essential to engage in multisectoral and multi-stakeholder collaboration.

Plenary 2. Making dementia a priority

PL2. Making dementia a priority

PL2-03Malta's 2nd National Dementia Strategy – 2024-2031

Alex Gobey
Dementia Care Directorate, AACC

The National Dementia Strategy for the Maltese Islands 2024 – 2031, titled 'Reaching New Heights', aims to significantly improve the quality of services and the quality of life of persons living with the condition in the Maltese islands. This dementia strategy is a continuation of the Maltese Islands' first national strategy and it builds on the sound progress made during its implementation. A review of the objectives implemented was carried out and new evidence-based practices were sought. Based on this assessment, various action areas were identified in the strategy to address what Malta needs to reach new heights in this care sector.

This plan spans over the period of the next seven years. It lays out a vision for how people with dementia might live their lives as well as the necessary societal, policy, and service adjustments needed to facilitate this. The objectives to be achieved through the action areas include:

- Increase awareness and understanding of dementia by improving inclusivity and accessibility in community settings that maximize the opportunities for health, involvement, and security for everyone.
- Reduce the risk of developing dementia by taking precautionary measures, such as increasing physical activity, preventing and reducing obesity, promoting balanced and healthy diets, quitting smoking and alcohol use, encouraging social engagement, promoting cognitively stimulating activities, preventing and managing diabetes, hypertension, and depression.
- Obtain an early diagnosis to enable individuals to make advance care and legal planning while they are still able to make important decisions.
- Instill a positive approach and empowerment, focused on helping persons with dementia and their families to live well with the condition.
- Improve education and training to develop a dementia-capable workforce with skills to deliver high-quality services and support.
- Strengthen seamless integrated person-centred care across all settings.
- Advance towards better dementia prevention, diagnosis, treatment, and care by implementing dementia research.

Plenary 2. Making dementia a priority

PL2. Making dementia a priority

PL2-04From dementia to brain health – the example of the Swiss Brain Health Plan

Giovanni Frisoni
HUG/UNIGENEVA

The "Swiss Brain Health Plan" (SBHP) was conceptualized to value, promote, and protect brain health over the entire life course. The following fundamental considerations of the SBHP are: (1) the high (and increasing) burden of brain disorders in terms of prevalence (>50% of the population suffers from a brain disorder), disability, mortality, and costs; (2) the prevention of brain disorders; (3) the operational definition of brain health; (4) determinants of brain health; (5) international initiatives to promote brain (including mental) health including the World Health Organization (WHO) intersectorial global action plan on epilepsy and other neurological disorders (NDs) (IGAP) and the WHO comprehensive mental health action plan. The five strategic objectives of the SBHP, which has the vision of promoting brain health for all across the entire life course, are: (1) to raise awareness; (2) strengthen cross-disciplinary and interprofessional training/educational programs for healthcare professionals; (3) foster research on brain health determinants and individualized prevention of brain disorders; (4) prioritize a holistic (non-disease-specific), integrated, person-centered public health approach to promote brain health and prevent brain disorders through collaborations across scientific, health care, commercial, societal and governmental stakeholders and insurance providers; (5) support, empower, and engage patients, caregivers, and patient organizations, and reduce the stigma and discrimination related to brain disorders. The first (2024) steps in the implementation of the SHBP are: (1) a definition of the overall organization, governance, specific targets, and action areas of the SBHP; (2) the patronage and/or co-organization of events on such specific topics as brain research (Lausanne), dementia (Geneva), stroke (Basel), neurohumanities (Bellinzona), sleep (Lugano), and psychiatry (Zurich); (3) the conduction of a new study on the global burden of brain disorders in Switzerland; (4) the launching of an international Certificate of Advanced Studies (CAS) on Brain Health at the University of Bern.

Plenary 3. Innovation in dementia care

PL3. Innovation in dementia care

PL3-01Digital Biomarkers to support dementia patients and their caregivers

Tobias Nef[1], Lena Bruhin[1], Markus Rueegsegger[2], Friederike Thilo[3], Pascale Schaub[3], Jacob Lahr[4], Stefan Klöppel[4]
[1]University of Bern, [2]University Hospital of Old Age Psychiatry, University of Bern, [3]Bern University of Applied Sciences, [4]University Clinic for Geriatric Psychiatry and Psychotherapy

Background:

The care of cognitively impaired patients in geriatric psychiatric facilities is a very demanding activity that requires well-trained and experienced professionals. The quality of nursing care is a decisive factor for well-being, patient safety and the effectiveness of medical interventions. However, it is very difficult for geriatric psychiatric facilities to recruit well-qualified staff. At the same time, the demands on nursing staff are increasing, as the proportion of qualified specialists per shift is decreasing and the proportion of multimorbid patients is increasing. This makes treatment on geriatric psychiatric wards very demanding. A large survey of Swiss nursing staff in various hospitals (https://matchrn.unibas.ch/) shows this very clearly. One of the greatest challenges for nursing staff, particularly at night, is to maintain an overview and decide which patient requires attention at any given time.

Research question:

This research project investigates whether the introduction of sensor-based digital nursing assistance systems can help nursing staff to keep track of patients on the ward, prevent unnecessary rounds, intervene quickly in emergencies and reduce stress for nursing staff. The study was conducted on a 22-bed geriatric psychiatric ward (Beyeler Ward, University Psychiatric Services Bern).

Method:

Sensors (radar, bed, and gait sensors) were placed in patient rooms, feeding data into algorithms that display patient status on smartphones. The system provides real-time information about whether a patient is sleeping, restless, about to get up, or has fallen. Alarms are customizable based on individual patient needs (e.g., for fall risk patients).

Results:

In February 2024, 1,502 alarms were triggered, with 500 during the day and 1,002 at night. Staff responded to 60% of alarms within one minute and 85% within three minutes. On

average, the system was used for 9 of the 22 beds (40.8%). Both patients and staff responded positively to the system.

Plenary 3. Innovation in dementia care

PL3. Innovation in dementia care

PL3-02Online peer support for people with Young Onset Dementia: more than just a replacement of in-person support

Esther Loseto-Gerritzen
University of Nottingham

People with Young Onset Dementia (onset before the age of 65) are more likely to be in paid employment and have different responsibilities within the family compared to older adults, posing unique challenges. As dementia is typically associated with older age, younger people often face stigma and social isolation. This can negatively impact their social network and levels of support.

Peer support, mutual support between people who have a similar health condition or life experience, can have a positive impact on one's social network. The reciprocal nature of peer support is empowering, and it allows people to share experiences, support, and coping skills. People with Young Onset Dementia describe peer support as 'a place where you feel normal' that 'gives hope that you can live well with dementia'. However, access to specialised services for Young Onset Dementia, including peer support, is often described as a 'postcode lottery': availability of such services varies widely across the United Kingdom. Online platforms could overcome this barrier, as people can engage regardless of where they are.

While research shows that people with Young Onset Dementia can experience the benefits of peer support in online settings, we must also be aware of the challenges. Digital exclusion, technological difficulties, and challenges around implementation and sustainability remain important barriers. This and the disparity of in-person peer support means that many people may miss out on the benefits of peer support. The current evidence

mainly relies on qualitative research, and there is a need for more quantitative evidence and feasibility studies, to support the implementation and sustainability of online peer support groups. Online connections cannot replace in-person human interaction. Instead, online and in-person peer support groups should co-exist, so that people with Young Onset Dementia can choose an option that suits their needs and preferences.

Plenary 3. Innovation in dementia care

PL3. Innovation in dementia care

PL3-03Virtual reality to promote the social connectedness of people living with dementia and their support persons

Aisling Flynn[1], Wei Qi Koh[2], Gearóid Reilly[1], Attracta Brennan[1], Sam Redfern[1], Marguerite Barry[3], Dympna Casey[1]
[1]University Of Galway, [2]University of Queensland, [3]University College Dublin

Introduction

People living with dementia often experience a lack of social connectedness, increased social isolation, and loneliness. This, in turn, can negatively impact their overall health, wellbeing, and ability to live well with dementia. To address this, digital technologies are increasingly being designed, developed, and implemented in dementia contexts to support social connectedness. Multi-user virtual reality (MUVR) is one such digital technology that has recently garnered increased attention in the dementia research landscape. MUVR facilitates real-time interaction and collaboration between two or more people within a shared virtual environment. To date, there is a paucity of MUVR and dementia research, particularly relating to its design and use for social connectedness.

Methods

To address this knowledge gap, a MUVR application was designed in partnership with people living with dementia and their support persons to promote or maintain their social connectedness. This qualitative, participatory action research study was completed over four phases. Multiple methods of data collection were used to gather data, including semi-structured interviews, online workshops, and observational field notes. Reflexive thematic analysis guided the qualitative data analysis process. To ensure that the research and MUVR

application design were guided by the needs and priorities of people living with dementia and their support persons, findings from each phase informed the subsequent phases.

Findings

Overall, the MUVR application was perceived as usable, acceptable, and feasible for people living with dementia and their support persons. They also deemed the application to have the potential to promote or maintain their social connectedness. This was attributed to the mutually meaningful content, the immersiveness of MUVR, and its novelty. The findings from this study also underscore several areas for future research, including intergenerational and distanced MUVR experiences for people living with dementia.

Plenary 3. Innovation in dementia care

PL3. Innovation in dementia care

PL3-04Collaborative innovation from development to implementation – The Partner in Balance journey within the ELICIT Framework

Lizzy Boots
Maastricht University

Co-creation is becoming increasingly important in academia. Many studies demonstrate that end-users should be included in the development phase of an intervention to ensure acceptance and effectiveness during the evaluation phase. However, co-creation should be an essential part of each step from development to implementation. To demonstrate this, the co-creation journey of the eHealth intervention 'Partner in Balance' (PiB) will be discussed. PiB was developed to support informal caregivers of people with dementia to adapt to their new role and prevent overburdening. Over the last 10 years, PiB has transformed from an intervention idea (academia-driven) to an effective intervention that is marketed and implemented in daily care. Many lessons were learned throughout this journey, and many challenges still arise every day in this innovative collaboration between academia, care practice and business. The Evaluation in Life Cycle of Information Technology (ELICIT) framework will be used to illustrate PiB's challenges and how end-users can be involved as co-creators within the cycle from business case assessment to summative evaluation.

Plenary 4. Intersectionality in dementia

PL4. Intersectionality in dementia

PL4-01The importance of gender in dementia research

Antonella Santuccione Chadha
Women's Brain Project

Alzheimer's disease (AD) is a debilitating neurodegenerative disorder with a higher prevalence in women. Recent innovations in disease-modifying treatments, plasma biomarkers, and digital technologies are revolutionising the management of AD.

Nevertheless, the impact of sex and gender remains to be better understood in AD. The Women's Brain Foundation conducted an analysis on latest research on the impact of sex and gender in modifying diagnostic and therapeutic pathways for Alzheimer's disease. We also analysed how emerging biomarkers and digital technologies are being used to enhance diagnosis and treatment personalisation, alongside an analysis of relevant policy and industrial trends. Finally, we addressed lifestyle interventions and cognitive assessments tailored to sex and gender.

Plenary 4. Intersectionality in dementia

PL4. Intersectionality in dementia

PL4-02Reaching out to and including minority ethnic groups in dementia research

T. Rune Nielsen, T. Rune Nielsen
Danish Dementia Research Centre

Due to demographic aging, the number of people with dementia in minority ethnic groups in Europe is predicted to rise dramatically in the next few decades. Despite the apparent need for timely diagnosis and care, several studies find lower diagnostic rates and service use in minority ethnic groups compared to majority populations. The lack of access to culturally sensitive assessment and diagnostic tools for dementia is a major challenge facing people with dementia from minority ethnic groups and their families.

This may impact on initial help seeking and on receiving an accurate diagnosis, and may contribute towards people from minority ethnic groups not being diagnosed or being diagnosed at a later stage of dementia. In the TIMING study, we aimed to improve timely diagnosis of dementia in people from minority ethnic groups by a) identifying challenges in cross-cultural dementia diagnostics to inform recommendations for clinical practice, and b) validating new culture-sensitive dementia case-finding tools. Reaching out to and including minority ethnic groups was central to all research questions, and people from minority ethnic groups were included as research participants, in Public Involvement work, and as members of the scientific team.

Plenary 4. Intersectionality in dementia

PL4. Intersectionality in dementia

PL4-03Queering up dementia: the next steps

John Angel Bond[1], Mike Parish[2]
[1]University of Stirling / LGBTQ+ Dementia Advisory Group CIC, [2]LGBTQ+ Dementia Advisory Group CIC

The number of LGBTQ+ individuals living with dementia is steadily increasing. However, their unique needs are often underrepresented and misunderstood in mainstream dementia care. This presentation aims to reshape the approach to dementia care by addressing the intersecting challenges faced by LGBTQ+ individuals with dementia, such as stigma, discrimination, and a lack of culturally competent care. These challenges can result in increased isolation, anxiety, and poorer health outcomes for LGBTQ+ individuals.

The presentation will begin by examining the historical and social factors that contribute to the marginalisation of LGBTQ+ people living with dementia in care settings, including past experiences of discrimination that may lead to a lack of trust in care providers. It will then shed light on the gaps in current dementia care practices, which often overlook the diverse identities and needs of LGBTQ+ patients due to a one-size-fits-all approach.

The importance of developing inclusive and affirming care practices that respect and celebrate the identities of LGBTQ+ individuals with dementia will be discussed. This involves training health and social care providers on LGBTQ+ cultural competence, revising intake forms and care protocols to be more inclusive, and creating safe and

welcoming environments in care facilities. Carer recruitment is also an important tool for ensuring care providers prevent cultural dissonance. Additionally, emphasis will be placed on the need for advocacy and policy changes that protect the rights of LGBTQ+ people living with dementia, ensuring they receive the same level of care and respect as their non-LGBTQ+ peers.

Finally, the presentation will provide practical, actionable steps for health and social care professionals, caregivers, and policymakers to implement these changes, moving beyond awareness to active inclusion. By taking this approach, we can ensure that LGBTQ+ individuals with dementia are treated with the dignity, respect, and compassion they deserve.

Plenary 4. Intersectionality in dementia

PL4. Intersectionality in dementia

PL4-04Inclusion of people with Down syndrome across the Alzheimer's disease Continuum

Eimear McGlinchey
Trinity College Dublin

Down syndrome is a genetic form of Alzheimer's disease, where virtually all individuals with Down syndrome develop Alzheimer's disease neuropathology by age 40, with a lifetime risk of dementia exceeding 95%. Alzheimer's disease is now the leading cause of death (~70%) in this population, contributing to a life expectancy over 20 years lower than that of the general population.

Despite this, people with Down syndrome are often excluded from research across the Alzheimer's disease continuum. This exclusion occurs at all stages, from prevention-focused clinical trials to post-diagnostic care considerations. Such exclusion exacerbates existing inequities in healthcare and research, limiting access to critical Alzheimer's disease treatments and care.

Recently, however, there has been progress in addressing some of these gaps. In Ireland, post-diagnostic dementia support guidelines were developed specifically for people with intellectual disabilities, including those with Down syndrome. These guidelines aim to

improve the quality of life for individuals living with intellectual disabilities and dementia by ensuring equitable and accessible post-diagnostic care and support.

Intersectional factors also exist within the Down syndrome population itself, including racial, socioeconomic, and geographical disparities. These intersecting factors highlight the need for a more inclusive approach that considers the diverse experiences of people with Down syndrome across different contexts and backgrounds.

To address this compounded inequality, there is a pressing need for greater inclusion of people with Down syndrome from low- and middle-income countries in global Alzheimer's disease initiatives. In consideration of intersectionality in the context of dementia, this talk will specifically explore the necessity of including all people with Down syndrome in Alzheimer's disease research, including those in the Global South.

Plenary 5. Brain health and prevention

PL5. Brain health and prevention

PL5-01Healthy ageing until age 100 – is it possible to escape dementia?

Daniela Jopp[1], Adar Hoffman[1], Armin von Gunten[2], Francois Herrmann[3], Stefano Cavalli[4], Swiss100 Team[5]
[1]University of Lausanne, [2]CHUV, [3]HUG, [4]SUPSI, [5]

After retirement age, the prevalence of dementia is doubling every decade. Consequently, at age 100, almost all centenarians should be affected by cognitive limitations. This, however, seems not to be the case. In the SWISS100 Study, the first nation-wide centenarian study in Switzerland, we investigated over 400 centenarians, in a phone study (n = 169; M_{Age} = 102.01, SD_{Age} = 1.71; females 75%) as well as in the main study with in-person interviews (n = 277; M_{Age} = 101.80, SD_{Age} = 1.43; females 78%). Centenarians were recruited from address data provided by the Statistical Office of Switzerland. Study findings based on proxy information revealed that 80% of the main study participants had never received a dementia diagnosis, and for those who did, the diagnosis was made after age 85. Using a 6-item version of the MMSE (max score 6; Haubois et al., 2013), there were 47% of the phone study participants with signs of cognitive impairments. In the main study, using the established Short MMSE (max score 21; Holtsberg et al., 1995), we found among the participants we were able to visit that 57% were cognitively intact, 21% had some restrictions, 13% had moderate cognitive restrictions, and 9% were strongly impaired.

Interviewer ratings via the Global Deterioration Scale (Reisberg et al., 1982) were in line with these results: 67% had no or very mild impairment, 9% MCI, 20% clear-cut deficits, and 3% had severe dementia. We also found notable heterogeneity in other measures (e.g., fluency test animal naming).

In sum, SWISS100 findings from different indicators confirm that being affected by dementia is not a natural fate for centenarians, which is in line with prior centenarian studies. Findings further indicate that there is a high heterogeneity of cognitive capacity among centenarians, suggesting various factors influence cognition other than age.

Plenary 5. Brain health and prevention

PL5. Brain health and prevention

PL5-03Artificial intelligence and risk prediction

Ira Haraldsen[1], Ira Haraldsen[2]
[1]Oslo University Hospital , [2]Oslo University Hospital

Artificial intelligence has emerged as a transformative tool in the field of dementia research, offering promising advancements in risk prediction and early diagnosis. Dementia, characterized by progressive cognitive decline, imposes a significant health burden worldwide. Early detection will be critical for timely intervention, yet conventional diagnostic methods often fall short in identifying individuals at risk during preclinical stages. AI, through its ability to analyze large and complex datasets, enables more accurate risk stratification by integrating diverse inputs such as genetic data, neuroimaging, and electronic health records. Machine learning models, particularly deep learning algorithms, can uncover subtle patterns that are imperceptible to human observers, thereby enhancing predictive accuracy. Recent studies like AI-Mind, have demonstrated AI's potential in predicting the onset of dementia years before clinical symptoms emerge, allowing for more effective planning and intervention. However, despite these promising developments, several ethical challenges remain regarding data privacy, model interpretability, and generalizability across different populations and information despite lack of efficient treatments. Further research is needed to refine AI models to ensure they are clinically applicable and ethically sound. By addressing these challenges, AI can revolutionize dementia care, shifting the focus from reactive treatment to proactive risk management, ultimately improving patient outcomes and reducing the global burden of this disease.

Plenary 5. Brain health and prevention

PL5. Brain health and prevention

PL5-04New prevention approaches for vascular dementia

Bogdan Draganski
Neurozentrum Inselspital Bern

Given the high prevalence of microvascular brain changes in the general population beyond the sixth decade, there is much effort focusing on understanding the underlying processes and linking individuals' lesion pattern to clinical signs and symptoms. Until recently, the incidental findings of a few white matter hyperintensities was considered part and parcel of normal ageing, whilst the finding of more extended ones – a mere consequence of poorly controlled cardio-vascular risk factors. Clinical observations and dedicated research studies brought empirical evidence about the detrimental effect of microvascular lesions – i.e. small vessel disease, on our cognitive abilities. Particularly intriguing is the challenging differentiation between white matter lesions related to cardio-vascular risk and the subtle signs of amyloid angiopathy, which is a feature of Alzheimer's disease.

In my presentation, I will touch upon newest epidemiological and clinical data on small vessel disease to make the case for primary prevention rather than efforts treating the risk factors after the damage has occurred. Additionally, I will stress the issue that there are specific lifespan periods with increased vulnerability for the deleterious effects of modifiable lifestyle factors that are further modulated by non-modifiable genetic risk.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-01Wealth, income and dementia in Germany: longitudinal findings from a representative survey among the oldest old

Snorri Rafnsson[1], André Hajek[2], Hans-Helmut König[2], Razak M Gyasi[2]
[1]The Geller Institute of Ageing and Dementia, University of West London, [2]

Objectives: Our purpose was to examine the association between income, wealth, and dementia among the oldest old in Germany. Methods: We used representative longitudinal data from a survey which assessed quality of life and subjective well-being of individuals aged 80+ years in North Rhine-Westphalia (Germany). Follow-up was about 2 years. The sample included community-dwelling and institutionalized individuals, with 943 observations included in the analysis. The average age of the participants was 86.0 years (SD: 4.0 years). Probable dementia was assessed by DemTect, a widely accepted screening instrument. Common income and wealth categories were used to quantify these variables. Results: After adjusting for sociodemographic and health variables, logistic regressions showed that higher wealth was associated with a lower likelihood of probable dementia (second lowest wealth quartile compared to lowest wealth quartile: OR: .23, 95% CI: .07-.76; second highest wealth quartile: OR: .05, 95% CI: .01-.31; highest wealth quartile: OR: .12, 95% CI: .02-.91). In contrast, income was not significantly associated with the likelihood of probable dementia. Conclusion: Our study demonstrated a relationship between wealth and dementia. Such knowledge can enrich the poverty and inequality research within this field. Our findings support to evidence-based policies aiming to decrease the burden of dementia in later life through reduction in economic inequalities or better income distribution.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-02Preventing cognitive and physical impairments: an innovative approach to intracranial atherosclerotic diseases in dementia research

Lu-Chiu Huang[1], Chih-Yuan Lin[2], Lu-Chiu Huang[3]
[1], [2]Taipei City Hospital/Neurology Department, [3]Taipei City Hospital/Departement of Nursing

Background: Intracranial atherosclerotic diseases (ICAD) are a significant risk factor for brain health decline and have been identified as a potential target for preventing cognitive and physical impairment. We present our approach to integrating neurology, internal medicine, traditional Chinese medicine, social work, clinical psychology, pharmacy, nutrition, and nursing to prevent and delay the onset of cognitive impairment. Methods: To provide care for this high-risk cohort exhibiting potential stroke risk and emerging neurological symptoms, thereby preventing cerebrovascular diseases while delaying or mitigating cognitive impairment and disability, we analyzed each patient's individualized

disease profile through a four-day short-term hospitalization. We conducted comprehensive cerebrovascular disease risk factors assessments during hospitalization, facilitated precise consultations with relevant specialties, and integrated complementary traditional Chinese medicine therapies. In the event of future acute cerebrovascular episodes, early identification and prompt management can mitigate cognitive impairment and disability. Consequently, our "Brain Wellness" program aims to leverage the combined benefits of lifestyle and health preservation strategies from conventional and traditional medicine domains, facilitated by a multidisciplinary team and holistic patient care paradigm, to prevent cerebrovascular diseases and delay cognitive impairment and disability. Assessment tools employed include the National Institutes of Health Stroke Scale and the Barthel Index for functional and clinical effectiveness evaluation; anxiety scales, quality of life measures, and a knowledge and behavior questionnaire specifically developed to assess cerebrovascular risk factors as patient-reported outcomes, complemented by a satisfaction survey as a patient experience measurement instrument. Results: Our program encompasses pilot testing and main-field testing to evaluate the feasibility and effectiveness of the intervention. Based on preliminary findings for 30 users with 100% satisfaction, good cardiovascular knowledge, and improved behavioral skills. Conclusion: Our integrative service program has proven effective in enhancing public knowledge and promoting healthy behaviors related to brain health.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-03A multidomain lifestyle intervention to maintain optimal cognitive functioning in older adults - baseline characteristics of the FINGER-NL randomized controlled trial

Kay Deckers[1], Marissa D. Zwan[2], Lion M. Soons[2], Lisa Waterink[2], Sonja Beers[2], Sofie van Houdt[2], Berrit Stiensma[2], Judy Z. Kwant[2], Sophie C.P.M. Wimmers[2], Rachel A.M. Heutz[2], Jurgen A.H.R. Claassen[2], Joukje M. Oosterman[2], Rianne A.A. de Heus[2], Esther Aarts[2], Sebastian Köhler[2], Wiesje M. van der Flier[2]
[1]Maastricht University / Alzheimer Centrum Limburg, [2]

BACKGROUND: Embedded in the World-Wide FINGERS initiative, FINGER-NL aims to investigate the effectiveness of a 2-year multidomain lifestyle intervention on cognitive functioning in older Dutch at risk individuals. PARTICIPANTS: 1210 adults between 60-79

years old with presence of ≥2 modifiable risk factors and ≥1 non-modifiable risk factor for cognitive decline were recruited between January 2022 and May 2023 via the Dutch Brain Research Registry and across five study sites in the Netherlands. METHODS: Multi-center, randomized, controlled, multidomain lifestyle intervention trial with a duration of 24 months. Participants were randomized to either a high-intensity or a low-intensity intervention group. The multidomain intervention comprises a combination of 7 lifestyle components (physical activity, cognitive training, cardiovascular risk factor management, nutritional counseling, sleep counseling, stress management, and social activities) and 1 nutritional product (Souvenaid®). The high-intensity intervention group receives a personalized, supervised and hybrid intervention consisting of group meetings (on-site and online) and individual sessions guided by a trained lifestyle coach, and access to a digital intervention platform that provides custom-made training materials and selected lifestyle apps. The low-intensity intervention group receives bi-monthly online lifestyle-related health advice via the digital intervention platform. Primary outcome is 2-year change on a cognitive composite score covering processing speed, executive function, and memory. RESULTS: Within 17 months, participant recruitment has been successfully completed (N=1210; mean age: 67.7 years (SD: 4.6); 64% female). Modifiable risk factors commonly present at baseline were physical inactivity (89%), low mental/cognitive activity (50%), low social engagement (39%), hypertension (39%) and high alcohol consumption (39%). The mean body mass index of participants was 28.3 (SD: 4.2) and the total serum cholesterol was 5.4 mmol/L (SD: 1.2). CONCLUSION: Baseline lifestyle and clinical measurements showed successful recruitment of participants with sufficient potential for prevention.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-04The association between socioeconomic status, LIBRA, and cognitive performance in older adults at risk of cognitive decline: a cross-sectional study

Lion Soons[1], Kay Deckers[2], Marissa Zwan[2], Sophie Wimmers[2], Lisa Waterink[2], Nynke Smidt[2], Jurgen Claassen[2], Yannick Vermeiren[2], Wiesje van der Flier[2], Sebastian Köhler[2]
[1]Maastricht University, [2]

Background: Modifiable dementia risk scores, such as the ‘LIfestyle for BRAin health’ (LIBRA) index, are useful tools for the identification of high-risk individuals who may

benefit the most from lifestyle interventions. Socioeconomic status (SES) has been suggested to influence both lifestyle and dementia risk. The current study investigated associations of SES and LIBRA with cognitive performance in older adults at risk of cognitive decline. Methods: We used cross-sectional data from the Dutch FINGER-NL trial, a multi-domain, randomized controlled lifestyle intervention study among 1210 adults aged 60 to 79. SES was determined by equivalent household income, which was divided into low, middle, and high based on tertiles. The LIBRA index was used as a weighted compound measure of 12 modifiable dementia risk factors. Overall cognitive performance was assessed by averaging test scores of a neuropsychological test battery for memory, processing speed, and executive functioning. We used multiple linear regression analyses, adjusted for age, sex, level of education, and study site, to study the associations of SES, LIBRA, and their interaction on cognitive performance. Results: A total of 1048 participants (mean age 67.5, 37.9% men) had available data on SES, LIBRA, and cognition. Participants in the middle and highest SES tertile showed significantly better cognitive performance compared to the lowest tertile (middle versus lowest: β =0.14, p=0.044; highest versus lowest: β =0.22, p=0.003). A one point increase in LIBRA scores (i.e., a less healthy lifestyle) was associated with poorer cognitive performance (β =-0.02, p=0.036). When adjusting for LIBRA, associations of SES with cognition attenuated slightly but remained significant for the highest SES tertile as compared to the lowest SES tertile (β =-0.18, p=0.010). No significant interaction of SES and LIBRA was found. Conclusion: Participants with a high SES showed better cognitive performance compared to low SES independent of modifiable dementia risk factors.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-05Motivational strategies to improve adherence to dementia preventive lifestyle changes

Stefan Klöppel[1], Esther Brill[2], Giovanni B. Frisoni[2], Dag Aarsland[2], Verena Klusmann[2]
[1]-, [2]

Lifestyles reducing dementia risk typically combine physical and cognitive training as well as nutritional adaptations and remain efficacious into early manifest stages of dementia. For efficacy, lasting changes of the lifestyle is mandatory, necessitating robust motivation and volition. Even in well-designed studies including FINGER [1], little more than half

completed all components of that life-style intervention. In clinical routine, motivation is frequently induced by negatively-framed, fearful statements ("If you don't change your lifestyle, you may get demented") [2]. While dementia-worry is widely present and strong [3], research on doctor-patient communication shows advantages of positively-framed information (e.g. "if you exercise, you may get to like it and it helps securing your autonomy" [4]). We are unaware of studies investigating effects of framing style on long-term behavioural changes but data supports effects on intended adherence [5]. We recently suggested to employ the long recognized motivational and volitional power of values to aid health promotion into old age [6], [7]. This approach can be well supported by smartphone-based reminders informed by ecological momentary assessments (EMA) or continuous sensing and integrates into a remote memory clinic [8]. In the presentation, we will summarize the existing evidence and illustrate how sensing technology and just-in-time adaptive interventions (JITAIs) can support motivation and volition. We report on the implementation of a manual for a consultation in the memory clinic that seeks to increase intended adherence through value-based motivation. We will report on a study comparing differently framed instructions in the memory clinic. The topic holds high clinical and preventative relevance given the leverage of behaviour change towards healthy ageing and reduced progression in symptomatic individuals. Supported by technology, this approach can be resource efficient and broadly distributed. In case of positive pilot interventions, an integration into large studies e.g. the worldwide FINGER campaign would be warranted [9].

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-07Exploring the potential for dementia risk reduction: 10-year findings with the lifestyle for brain health (LIBRA) index

Veerle Van Gils, Kay Deckers
Maastricht University

Background: Dementia risk reduction strategies should be informed by presence of readily available risk factors that are truly amenable to change. The Lifestyle for Brain Health (LIBRA) index was developed to quantify an individual's 'room for improvement' and has been extensively validated in multiple observational and intervention studies, and against different outcomes. Method: Following a systematic review and Delphi consensus study in 2013/4, twelve modifiable dementia risk and protective factors were included in LIBRA: physical inactivity, smoking, alcohol use, cognitive activity, Mediterranean diet, depression,

hypertension, obesity, diabetes, hypercholesterolemia, coronary heart disease, renal disease. Weights based on each factor's relative risk are summed up in a total score, with higher scores indicating a worse brain-healthy lifestyle. Results: In observational studies, a worse LIBRA score has been consistently associated with a higher risk for cognitive decline and dementia, lower brain grey matter volumes, more white matter damage, a higher brain age and worse structural connectivity. In addition, LIBRA has been shown to be sensitive to change in the FINGER, MAPT, preDIVA and HATICE lifestyle trials. LIBRA has been widely implemented in other intervention studies as a secondary outcome, and in public health campaigns and mHealth tools to raise awareness and inform individuals about their prevention potential. In 2023, the index has been updated by an umbrella review and expert consensus study to include weights for hearing loss, sleeping problems and social interactions. Discussion: A worse brain-healthy lifestyle summarized by LIBRA has been shown to be associated with a wide range of poor structural and functional neural markers. LIBRA is a useful tool for selecting participants into lifestyle-based trials, informing people about their risk profile, and monitor outcome in lifestyle-based prevention initiatives.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-09Measures to enhance health behaviour and reduce dementia risk among adult residents in Norwegian municipalities - a qualitative study

Anne Marie Mork Rokstad, Grete Kjelvik, Geir Selbæk
Norwegian National Centre for Ageing and Health, Vestfold Hospital Trust

Aim: The purpose of the study is to investigate the knowledge of risk factors for dementia among key stakeholders responsible for public health in Norwegian municipalities. The experiences of measures used to enhance health behaviour and reduce dementia risk among adult residents are explored. Method: A qualitative descriptive design is applied using focus groups to collect data from eight municipalities. The sample of 46 participants include various stakeholders in the communities like politicians, public health physicians and coordinators, leaders in health and social care services and coordinators of other departments in the municipality like the voluntary or cultural sector. Results: The preliminary results reveal that the participants have sufficient knowledge of the main risk factors of dementia and the possibility to use measures to reduce the risk of dementia in old age. They describe municipalities' health preventive experiences and give examples of implemented measures tailored to the general public (between 30-70 years old), the elderly population (70+ years)

and groups at higher risk of dementia. Different barriers in preventive health work and opportunities for future strategies are discussed. Lack of priority of primary prevention including the challenges in evaluating future effect of health preventive actions made today, is a challenge. So are cultural differences in health literacy. The need for further investment in the voluntary sector and public information campaigns supported by national authorities are described. Individual guidance and follow-up of those at higher risk of dementia disease should be implemented. Conclusion: Based on the experiences of preventive health measures to reduce the risk of dementia, the municipal stakeholders focus the need for further collaboration with the voluntary sector. Public information campaigns combined with individual guidance and follow-up of those at higher risk of dementia are needed. Municipal actions need the evidence-based guidance and support from national authorities.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-10IN FORMA MENTIS: an integrated prevention program of cognitive training, physical activity and nutrition. preliminary results of a pilot study in Modena (Italy)

Annalisa Baglieri[1], Laura Bernaroli[2], Cecilia Zurlo[2], Ylenja Persi[2], Lisa De Pasquale[3], Petra Bevilacqua[4], Antonella Rita Vaccina[4], Paola Patrizia Morana[4], Gustavo Savino[2], Andrea Fabbo[4]
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Background: In dementia prevention field, recent findings suggest lifestyle can significantly reduce risk of dementia, identifying cognitive training, physical activity, healthy nutrition and socialization among main neuroprotective factors.
Purpose of the study: The aim of this study is to evaluate beneficial effects of "In Forma Mentis", an integrated group prevention program of cognitive training, physical activity and nutrition, on memory self-perception and on psycho-physical well-being.
Methods: The program was developed by Cognitive Disorders and Dementia Center and the Sport Medicine Service. A sample of 34 people from 60 to 85 years without cognitive

impairment was recruited. The program included 10 weekly meetings lasting 2 hours. Specifically, 8 meetings concerned to memory meta-cognition, cognitive stimulation, learning strategies combined with physical activity and 2 meetings based on healthy nutritional education. Partecipants were also given homework to do during the week. Addenbrooke's Cognitive Examination (ACE-R), Geriatric Depression Scale (GDS) short form, Short Physical Performance Battery (SPPB) and Memory Assessment Questionnaire (MAC-Q) were administered before the intervention (T0), at the end of the intervention (T1) and after a maintenance program (T2). Descriptive statistic, paired and independent t-test, mixed effects model for repeated measures were performed.
Results: Our sample had a mean age of 73.5±7.4. Mean scores at T0 were 89.9±7.6 for ACE-R, 10.5±1.4 for SPPB, 2.7±2.8 for GDS and 24.7±3.2 for MAC-Q. Preliminary analysis showed that MAC-Q scores decreased statistically significantly compared to T0 scores with p value <0.001 (T1: 16.1 and T2: 18.2), with a maintenance at T2. SPPB scores remained constant overtime, while ACE-R (T1: 91.2 and T2: 92.9) and GDS scores (T1: 1.9 and T2: 1.6) improved after the program.
Conclusions: "In Forma Mentis" presents promising preliminary results in dementia prevention, highlighting positive effects on perception of own memory, on cognitive performance, on mood and physical functioning in aging population.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-100The use of a therapy ball (technical device) as part of social care for residents with moderate to severe cognitive impairments

Sophie Hellmann, Sascha Saßen
Korian Deutschland GmbH

Objective: The goal was to carry out a 3-month pilot project in six fully inpatient nursing homes using a therapy ball as part of social care in order to find out whether residents with moderate to severe cognitive impairments benefit from the use of the therapy ball as part of individual social care.
Target group(s): Residents of fully inpatient care facilities (with dementia, some bedridden); social care staff
Project content: Six fully inpatient nursing homes were equipped with therapy balls that provide multisensory stimulation via light, vibration and sound. During the planning of the pilot project, therapy games in the categories "memory", "movement", "music" and "bedside

care" were selected and stored in fixed profiles on the balls. At the beginning, face-to-face training sessions were held in the facilities. The social care staff was given background information on how the ball works and were able to try out the various therapy games. In the facilities, a fixed selection of residents was chosen by the social care team for the individual care with the ball according to predefined criteria. These residents were activated with the therapy ball at least once a week during the project period. Each individual social care session was evaluated by the employees in a questionnaire. The staff were also asked about their own experiences with the therapy ball using a questionnaire. During the project, support was provided by a consultant from Central Quality Management and by the company that developed the therapy ball.
Project results: The evaluation of the questionnaire results shows positive results. A total of 450 individual social care sessions were carried out during the project period. The staff rated the work with the therapy ball as positive and helpful. The six facilities continue to use the therapy ball even after the project ended.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-101Cost-consequence analysis of the Partner in Balance program for informal carers of persons with dementia

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Introduction: Most informal caregivers emphasize the pressing need for efficient caregiver support mechanisms, indicating the need for additional support. Partner in Balance (PiB), a blended self-management program for informal caregivers of persons with dementia, presents a promising avenue for providing cost-effective support. This study aims to evaluate the cost-consequence of PiB compared to usual care.
Methods: A cost-consequence analysis from a healthcare perspective was conducted within a randomized waiting-list controlled trial in the Netherlands. The study included 78 informal caregivers, assessing intervention and healthcare costs, and caregiver utility scores over an eight-week follow-up period. Bootstrapping and sensitivity analyses were performed to test the robustness of the results.
Results: Compared to standard care, PiB incurred significantly higher costs (€2,027 vs. €805) at eight weeks, with the largest cost differences found for intervention and nursing home costs. PiB's caregivers reported better, though not statistically significant, utility scores

(0.82 vs. 0.76). Sensitivity analyses supported the robustness of these findings. Conclusion: PiB presents a promising approach to supporting informal caregivers of persons with dementia, indicating higher initial costs but benefits in caregiver utility. However, the study presented too many limitations to make a confident reimbursement recommendation for the caregiver program. Therefore, we recommend awaiting further research assessing the long-term cost-effectiveness and broader societal impacts of PiB before deciding on its potential reimbursement.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-102Nature-based and Animal-assisted Intervention Strategies (NATAIS): a research agenda targeting social isolation and loneliness in people with neurodegenerative diseases

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Background: Social isolation and feelings of loneliness are common among individuals with neurodegenerative diseases and lead to a diminished quality of life and various negative outcomes. These issues were exacerbated during the COVID-19 pandemic, prompting initiatives to combat social isolation. Considering the potential benefits of nature-based and animal-assisted intervention strategies (NATAIS), it is imperative to explore how these approaches might mitigate the adverse effects of social isolation and loneliness in this population. Therefore, we aimed to develop a research agenda for NATAIS specifically tailored to individuals with neurodegenerative diseases, with a particular focus on addressing

challenges during times like pandemics.
Methods: to facilitate the development of the research agenda, a group concept mapping procedure was conducted. In total, 19 work group members (mainly form Europe and US) participated through a combination of in-person and online group meetings. Additionally, face-to-face group sessions were held at two innternational conferences, during which feedback was solicited from 12 experts in the field of NATAIS and psychogeriatrics.
Results: The group concept mapping procedure resulted in 14 clusters describing various future research topics, which were refined and detailed during group discussions. The remaining eleven clusters, encompassing important research themes within the field of NATAIS, were organized into a logic model and summarized into the research agenda. The overarching cluster ‘Ethical issues, possible risk factors, and their solutions’ was considered the most relevant during times of increased social isolation, such as during a pandemic, along with the 'Necessity for more accessible NATAIS'.
Conclusion: This project resulted in a research agenda, directing future research and fostering collaboration between practitioners and researchers in the field of NATAIS. Such an enhanced partnership between science and practice has the potential to significantly contribute to the well-being of people with neurodegenerative diseases, in their daily lives and also during pandemics.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-103The psychosocial needs of people with dementia living alone and the role of specialist dementia nurses in meeting these needs

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Dementia UK

The number of people with dementia who live alone is set to increase. People who live alone with dementia experience a shorter time to transition to residential care and often encounter health and social care services at the point of crisis. Supporting people who live alone presents challenges to health care providers including balancing a person’s rights and autonomy with the need to manage their safety and the concerns of others. Specialist dementia nurses (known in the UK as Admiral Nurses) have experience of navigating such complex and uncertain situations, and are therefore uniquely positioned to support people with dementia who live alone.

We present the findings of a systematic review that aimed to (1) summarise the psychosocial needs reported by people with dementia who live alone across the illness trajectory (diagnosis to bereavement) and (2) to consider what specialist dementia nurses can do to meet these needs.
The review identified 16 studies exploring the needs of people living alone with dementia. Needs were categorised based on Kitwood's model: love, comfort, inclusion, occupation, attachment, and identity. Studies revealed unmet needs across all domains, with loneliness, safety concerns, and loss of identity being prominent. The findings highlight the crucial role specialist dementia nurses can play. Their expertise in dementia care positions them to support these individuals through advocacy, education, practical support, emotional support and future care planning. Furthermore, the review demonstrates the benefits of building trusting relationships, assertive engagement and sensitive assessment, suggesting that a case management approach could be beneficial.
This review is being conducted alongside a review into the challenges experienced by family members providing care and support for people living with dementia from a distance, to form a coherent approach to addressing an identified research priority of people with dementia living alone and families caring from a distance.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-104Digital Photo-Activity effects on nursing home residents with dementia's social interaction and quality of life, and formal carers' empathy: a randomized controlled trial

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Background: The effects of a digital Photo-Activity (PA) versus a general conversation activity (control) on social interaction and quality of life of nursing home residents with dementia, and empathy of their formal carers were examined.

Methods: An explorative RCT was conducted in N=81 residents (n[ExpGroup]=40) and 51 formal carers (n[ExpGroup]=23) with three measurements (pre/post-test, 2 week follow-up). Primary outcomes: INTERACT subscales measured residents' social interaction during the intervention, and QUALIDEM subscales measured residents' quality of life. Secondary outcome: Interpersonal Reactivity Index (IRI) measured formal carers' empathy. ANCOVA's were performed to analyze post-test data, with pre-test scores as covariate, and interaction effects between dementia severity (DS; low or high) and group (PA or control). Multi-level analyses (MLA) were done for QUALIDEM at three time-points.
Results: PA residents scored significantly higher on INTERACT subscale Mood (p=.037, ηp2=.07), than controls at post-test. PA residents with low DS scored significantly higher in the INTERACT subscales: Mood (p=.017, ηp2=.092), Stimulation Level (p=.011, ηp2=.106) and Need for Prompting (p=.013, ηp2=.099) compared to controls. The opposite effects on the same subscales were seen for PA residents with high DS. PA residents (p= .025, ηp2= .082, M=15.2, SD=3.69) scored significantly higher on the QUALIDEM subscale Positive Affect compared to the control group (M=13.69, SD=3.85) at post-test, and follow-up (MeanPA= 15.28, MeanControl= 13.93, p=.042, d=.39). No significant differences were found in the other INTERACT or QUALIDEM subscales. PA formal carers showed a significant decline in empathy (IRI; p=.006, ηp2=.185; M=59.58, SD=6.43) compared to controls (M=62.36, SD=8.70) at post-test.
Conclusion: Based on these findings, examining the effects of the PA in a larger sample of residents with low DS is worthwhile. The effects on empathy of PA formal carers could be due to focusing more on residents' personhood rather than disabilities. This needs further investigation.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-105REWIRE: a new tool to prevent cognitive decline and emotional fall in people next to retirement

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Background: Retirement is one of the top ten stressful events experienced by ageing individuals. The transition from a working status to that of retirement reshapes health behaviours and social interactions and subjects the individual to psychosocial stresses.

Retirement has been associated with cognitive decline and psychosocial seclusion, whose acme is situated in the first year after retirement. First, we aim to develop a user-friendly retirement cumulative risk index capable of summarising the psychosocial and cognitive factors that can predict who is at risk of stressful retirement. Then, we would promote and test the effect of a series of tailored interventions to improve retirement outcomes, prevent cognitive decline, and increase healthy life years.
Methods: 1st WP: 2000 on-pension participants will support the development of the risk index by responding to an online questionnaire capturing emotional, cognitive, and psychosocial inputs, economics one included. 2nd WP: 180 on-pension participants will participate in a series of activities: 90 participants are offered a multi-component physical conditioning programme added with environmental uncertainty, task-switching, and action anticipation requirements. Each session lasts 45 minutes and involves participants in open-skill and aerobic actions.
Expected results: We expect to validate the cumulative risk index to test its "diagnostic" value and whether it can be modulated/attenuated by a tailored intervention. The risk index will be defined as a list with an odd ratio rate for each relevant risk factor. It will generate a personalised risk index and constitute a valuable prevention and intervention tool.
Conclusions: Millions of Europeans will go through retirement in the forthcoming years. REWIRE will produce robust quantitative empirical evidence for the risk of a negative transition to the retirement stage of life: Such a risk definition would suit the development of an evidence-based preventive policy-making path.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-106Needs assessment and determinants of relationship quality within the dementia care triad in long-term care facilities: a mixed-methods scoping review

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Background: In long-term care facilities, the quality of relationships within the dementia triad (residents living with dementia, their families and staff) has been demonstrated to be

essential for delivering high-quality care and promoting psychological wellbeing among all involved. This study aimed at reviewing scientific literature regarding the specific and shared needs of all involved parties, and key determinants influencing relationship quality.
Methods : We performed a mixed-methods scoping review (PubMed, CINAHL, PsychINFO and Cochrane) integrating qualitative and quantitative studies and the input from a working group consisting of 17 people, including researchers, informal and formal caregivers. We applied open codes in ATLAS.ti to describe all needs and determinants. Thematic analysis was conducted.
Results: Twenty-eight articles were included. Preliminary findings indicated that residents living with dementia have specific needs such as the encouragement of their independence in manageable tasks, and staff giving them sincere attention and showing personal interest. Examples of needs expressed by families were to be involved in small tasks, to have their perspectives acknowledged, to preserve their loved one's identity, and to receive psychosocial support from staff. Both residents and families expressed the need to being consulted and informed by staff more often. Shared needs among all involved included feeling valued and respected, compassion, and maintaining the dignity of residents with dementia. Effective (non-verbal) communication, trust, shared care philosophies, mutual goal setting, sufficient time and organisational support were examples of identified key determinants influencing relationship quality.
Conclusion: Data analysis is ongoing, with the final list of determinants and needs set to be presented at the conference. The results will be used to identify target areas for the design and implementation of a tailored psychosocial intervention for improving and sustaining relationships within the dementia care triad in long-term care facilities.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-107Qualitative study: a questionnaire to assess participants satisfaction at the meeting centres support programme in the Italian context of Formigine

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Background: Meeting Centers (MCs), born in the Netherlands, are a multi-componential and integrated psychosocial intervention that provide practical, emotional and social support to people living with mild to moderate dementia and their caregivers (CGs) in the community. The MC "Officina della memoria" born in 2022 in Formigine (Modena, Italy) opens 3 times a week for a total of 8 hours. It is currently lead by a Psychologist and 2 Occupational therapists (OTs); 20 volunteers help professionals to implement cognitive stimulation, occupations, physical or musical activities and games.
Objective: to assess participants satisfaction from a qualitative point of view.
Methods: Qualitative data were collected through a questionnaire with 12 items. The scoring scale is designed as a Likert scale and ranges from 0 to 4 (0= not at all, 1= a little, 2 = quite a bit, 3 = a lot, 4 = very much). The questionnaire was administered to people who had participated at least 6 months continuously by OTs during the open days of the MC. OTs also collected significant sentences expressed by participants during the questionnaire. Questions and answers were read while maintaining neutral intonation so as not to condition the response and to facilitate people with cognitive impairment and low educational background. In addition gender and age of participants were collected.
Results: The sample consists of 23 participants (13 F; 10 M) aged between 68 and 101.
15 people like to attend the MC "very much", 18 would like to continue "very much" to participate, 14 are satisfied with the services and 17 with the relationship with the staff, and 13 feel "very much" peaceful at the end of the meetings.7 participants would like "not at all" or "a little" to do activities with their CGs, 10 people feel they have made "quite" new friends.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-108Out-door activities with animal assisted interventions for people with dementia and their caregivers

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Dementia profoundly affects the social, physical, and mental well-being of individuals living with the condition, as well as their families and the community. Animal-assisted interventions offer a promising non-pharmacological therapy for dementia, with demonstrated benefits across demographics. In a joint effort, ARAD and AIASPORT initiated a project focused on implementing horse-mediated behavioural therapy for elderly individuals with cognitive disorders. The project's objectives include alleviating behavioural symptoms, enhancing the overall quality of life for patients and caregivers, promoting engagement in outdoor activities.
Weekly sessions were conducted at the Aiasport stables, offering participants the chance to partake in various horse care activities (feeding, grooming, leading the animal, etc) under the guidance of specialized instructors. Furthermore, ARAD neuropsychologists and volunteers provided psychological support. At least 8 elderly people aged over 75 yrs with mild to moderate dementia participated in each of the four completed cycles between 2022 and 2023. A fifth cycle is currently ongoing.
To assess the presence of behavioural disorders in participants and monitor changes over time, caregivers were administered the Neuropsychiatric Inventory Questionnaire – NPI-Q (Kaufer et al., 2000) before and after each cycle. Preliminary analysis of NPI-Q assessments show some improvement, but not statistically significant. In order to have a larger study sample, complete results will be available when completing the fifth cycle.
This project contributes to the understanding of non-pharmacological interventions for dementia care. While the initial findings from our study reveal no statistically significant reduction in symptoms based on the NPI-Q questionnaire, it's important to note the constraint of a limited participant sample size which poses challenges in assessing the outcomes comprehensively. Nonetheless, this project's endeavour remains committed to contributing to the broader body of knowledge in this field, aiming to find strategies to meaningfully improve the quality of life for those impacted by dementia and their caregivers.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-109Cognitive training for people with mild dementia

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In recent years, there has been an increase in the utilization of psychosocial interventions targeting dementia, with cognitive training (CT) emerging as a prevalent nonpharmacological approach. CT involves structured practice on specific cognitive tasks such as memory or problem-solving, aimed at enhancing or sustaining particular cognitive functions or overall cognitive capacity. These interventions are tailored to individuals with dementia, fostering cognitive abilities through group interactions and social engagement. Research has shown that CT benefits cognitive function and aspects of well-being in those with MCI, indicating its potential for broader implementation in dementia care (Raimo et al., 2023).
ARAD, a non-profit association focused on dementia research and care, partnered with CARISBO Foundation to introduce a comprehensive cognitive stimulation program for individuals with mild to moderate dementia. The program spans a year, consisting of four cycles, each lasting three months. Sessions occur twice a week, lasting two hours each. Prior to each cycle, a total of 15 participants were screened using the Mini-Mental State Examination (MMSE). The inclusion threshold was set at 22, indicating participants with mild dementia (Vyas et al., 2011). Nine participants met this criterion and were included in the study (M = 24.8; SD = 2.6).
Activities within the program are conducted using pen-and-paper formats designed to address various cognitive domains. The complexity of tasks varies to suit individual needs and abilities. At the end of the year, participants will take the MMSE again to see if their average scores have significantly changed due to the training.
The main goal of this initiative is to address cognitive decline and social isolation among elderly individuals with cognitive impairment. This is being achieved through structured cognitive training sessions and opportunities for social interaction. Ultimately, the project seeks to establish social networks and support systems for elderly individuals with dementia.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-11Could cerebral fructose metabolism be a driver of Alzheimer's disease? or, in lay terms, is every soft drink a bullet to our brain?

Helena Popovic
Outwitting Alzheimer's

Fructose is a simple sugar (monosaccharide), which when bonded with glucose makes table sugar (the disaccharide, sucrose). When humans consume too much fructose — particularly

in soft drinks and other sugary beverages — it leads to mitochondrial oxidative stress, local inflammation and progressive reduction in cerebral energy (ATP) levels. The fall in intracellular ATP generates uric acid, which leads to insulin resistance and reduced endothelial nitric oxide. All these factors lead to insufficient energy for neurons to remain functional and viable, eventually leading to the clinical picture of Alzheimer's. Fructose also alters hundreds of genes in the hippocampus and hypothalamus that regulate learning, memory, metabolism and hunger. Consuming fructose inhibits satiety (by inducing leptin resistance) which drives overeating and a self-perpetuating destructive spiral. Rats fed high amounts of fructose show a drop in their ability to learn and remember new information, accompanied by a shrinkage of their hippocampus after just one week. In addition, when glucose is consumed in excess (by eating a diet high refined starches), the glucose can be converted to fructose. The enzyme required for the conversion of glucose to fructose (aldose reductase) is enhanced in the presence of salt, alcohol or dehydration, all of which are modifiable dietary factors. This presentation is a review of the mechanisms by which sugar can contribute to Alzheimer's and other dementias. This is of critical importance given the ubiquity of sugar in our current diet and the potential to prevent dementia on a massive scale through reducing intake. If people understand the brain-damaging effects of excessive sugar consumption (especially when combined with salt and alcohol), they will be more motivated to make dietary changes. This knowledge also provides incentives for governments to regulate the marketing of ultra processed foods and drinks that are high in sugar, and to implement health warning labels.https://drhelenapopovic.com/

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-110Dual-task exercise intervention for visual processing speed and visuo-spatial working memory in older adults with cognitive impairment: a randomised controlled trial

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Loughborough University

Background: Exercise interventions could be effective in improving cognitive functions in people with dementia. However, the immediate effects of dual-task exercises on specific cognitive domains remain unclear.
Methods: Twenty-four older adults with and without dementia were randomly allocated to three groups: dual-task (resistance band and eye movement exercise), eye movement

exercise, and control. The assessor was blinded to group allocation. The study aimed to investigate the immediate effects of these interventions on Visual Sensitivity Test (VST), Hopkins Verbal Learning Test (HVLT) delayed score, Corsi Block-Tapping Test (CBT), and Verbal Fluency (VF).
Results: Significant interaction effects between time and intervention were found for VST ($p = .044$) and CBT ($p = .007$), suggesting differential effects of the interventions on these outcomes over time. No significant interaction effects or pairwise differences were observed for HVLT ($p = .666$) or VF ($p = .343$) at either time point (all $p > .05$). A significant improvement in CBT performance was observed following eye movement training compared to the control condition ($P<.05$).
Conclusion: The dual-task exercise intervention selectively improved visual search and spatial working memory, but not verbal learning or fluency, compared to the eye movement and control conditions in older adults with cognitive impairment. These findings highlight the potential of dual-task exercises for targeted cognitive improvements in this population. Additionally, individuals with cognitive impairment showed greater improvements in HVLT scores after eye movement training. Therefore, further exploration of eye movement training as a standalone intervention is warranted.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-111LE SANS FOURCHETTE® offers gastronomic solutions for those with neuro diseases and their entourage, promoting inclusive dining and training restaurateurs to adapt

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"LE SANS FOURCHETTE® " An approach to introduce pleasure, conviviality and intergeneration after 50 experiences and a future implementation. LE SANS FOURCHETTE® " offers a handheld meal without cutlery for people with progressive neurological diseases, their families and caregivers. The initiative aims to raise awareness of the invisible disability in the gastronomic world. With this in mind, the initiative is being carried out in collaboration with hospitality schools, with the aim of training the next generation of restaurateurs, integrating knowledge of this type of disability into their studies, and destigmatizing the disabled person. The main aims of "LE SANS FOURCHETTE®" are

twofold. On the one hand, to demonstrate that moments of pleasure, conviviality and sharing around meals for people with disabilities and illnesses and their families are made possible by adapting the food. To take this opportunity to enjoy a meal outside their home, emphasizing the pleasure of eating and sharing in a reassuring environment. Secondly, to make gastronomy professionals more aware of diseases such as Alzheimer's and similar disorders, and to encourage them to offer solutions adapted to the needs of these patients and their families. Our approach is designed to overcome preconceived ideas, to combat preconceived notions of maintaining social rules, and to create a warm and friendly atmosphere around meals.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-112WELLDEM: Feasibility of a positive psychotherapy intervention for people recently diagnosed with dementia

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The period following a dementia diagnosis is one of uncertainty and emotion, however, post-diagnostic support is variable and inconsistent. Positive Psychotherapy has been used to address the needs of people living with both mood disorders and psychosis, through structured programs tailored to these populations. This project set out to examine the feasibility of WELLDEM, a Positive Psychotherapy group program adapted for people living with dementia from a validated program for people living with psychosis. PPI and clinician focus groups were held to identify modifications required to create WELLDEM. Nine participants (3F/6M) who had been diagnosed within the previous two months, had capacity to consent, ability to communicate in English, and a minimum of 24 on the sMMSE or equivalent on other screening tools, were recruited through a memory assessment clinic. The program comprised 10 x 90minute structured sessions once per week, followed by a post-intervention individual interview to repeat the cognitive assessment, plus wellbeing and quality of life measures. All sessions were video recorded to capture the interactions and inform future development of the program based on the success of the activities. At the end of the WELLDEM program, cognitive, wellbeing and quality of life scores changed for some participants and not others, with both improvement and decline in the changers. All participants enjoyed attending the group and wished it would continue. They particularly enjoyed meeting other people in a similar situation, as well as activities such as relaxation

and savouring, as well as memory strategies. The findings demonstrated the feasibility of a Positive Psychotherapy approach for people living with dementia and provided insights into refining the program as a post-diagnostic support for people recently diagnosed with dementia.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-113Person-centered approach within group music interventions for people with dementia and depression

Naomi Larissa Rasing
University Medical Center Groningen

Background: Group music therapy and recreational choir singing were provided to people with dementia between mid-2018 to mid-2023 in the context of the multinational cluster-randomized trial Music Interventions for Dementia and Depression in ELderly care (MIDDEL). In Australia, Germany, the Netherlands, Norway, Türkiye and the United Kingdom, 21 Music therapists and 24 choir leaders provided weekly sessions according to a predefined session structure, in which specific session elements had to be provided. It is unknown what reasons people with dementia had not to participate in sessions and whether and how intervention providers tailored session content to align with preferences and current needs of individual residents in the group.
Method: At every session attendance and reason for non-attendance we noted by the intervention provider. Open text available in Dutch (Netherlands) or English (Australia and UK) were included in the analysis. In more than 150 GMT sessions and 150 RCS sessions observations, notes or thoughts were written down in an open text field. A focus group with intervention providers was conducted mid-June 2024 to assess whether findings resonate with practical experiences of intervention providers.
Objectives: The aim of this study was twofold: 1) to gain insight into non-attendance: what were reasons why some care home residents with dementia were, and others were not attending the group-based music interventions, 2) how were group-based music interventions person-centered: what specific actions intervention providers applied to make group music interventions person-centered.
Conclusion: Ultimately, findings will provide insight for daily practice into ways to tailor group interventions to individual residents with dementia.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-114The impact of music interventions on immediate stress in dementia: results of salivary cortisol and alpha-amylase assessments in a multinational cluster-randomized trial

Naomi Larissa Rasing
University Medical Center Groningen

Introduction: Stress negatively impacts well-being and quality of life in people with dementia, music may have a stress-reducing effect. We assessed the effect of music on immediate stress in Germany, Norway and the Netherlands as part of the MIDDEL cluster-randomized controlled trial (Music Interventions for Dementia and Depression in Elderly care). Participants: Care home residents were eligible for inclusion in this add-on study if they were participants in the MIDDEL trial. Participants with swallowing difficulties were excluded. Intervention: Participants were randomly allocated to group music therapy (GMT), recreational choir singing (RCS) or a control group receiving care as usual without music interventions. The control group participated in a book reading session on data collection days. Methods: At three timepoints, saliva samples were collected using SalivaBio Children Swabs at 10 minutes before, 15 and 60 minutes after GMT, RCS or a book reading session, along with a Visual Analogue Scale for Stress. Results: Informed consent was provided for 207 care home residents (45.3% of eligible participants) in Germany (n = 62), the Netherlands (n = 110) and Norway (n = 35). 1014 saliva samples were collected in 183 participants. 671 samples (66.2%) were valid for alpha-amylase assay and 633 samples (62.4%) for cortisol assay. Salivary cortisol, alpha-amylase, and subjective stress significantly changed from pre- to post-intervention within groups, although no significant difference was found between study arms. Discussion: Findings show it is feasible to collect saliva samples in persons with dementia. To the number of valid saliva samples, future studies should consider to stimulate saliva flow. Group interventions can have a positive impact on stress levels in care home residents with dementia. The level of intensity of participation required from the person with dementia may play a role in the impact of music on stress. ClinicalTrials.gov registration NCT03496675.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-115Informal caregivers of people with dementia in Germany: psychosocial characteristics and unmet needs

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[1]DZNE, [2]

Background: Caregivers of people with dementia living at home (CPwDh) are likely to be affected by a range of health problems. However, CPwDh are often regarded as accompanying persons and receive less attention in research and care. Little is known about this population and their needs in Germany. However, better knowledge of CPwDH is needed to design effective interventions.
Objective: The objective of this report is to describe the situation of CPwDh and highlight differences based on sex and living situation.
Methods: This was a cross-sectional analysis of the psychosocial characteristics of participants in the GAIN trial, a cluster randomized, controlled intervention trial investigating the effectiveness of a care management program. A total of n = 192 CPwDh were recruited in GPoffices, memory clinics or through public campaigns in the German federal state of Mecklenburg-Western Pomerania. The inclusion criteria were an age of 18 years or above, being a CPwDh, written informed consent. In a comprehensive digital assessment, psychosocial variables, burden, and care needs were assessed.
Results: Partners, women, and people living in the same household represented the majority of caregivers, and their mean number of needs was 8.7. Overall, participants indicated a mild to moderate burden. There are differences in burden based on sex and living situation, with caregivers living with people with dementia showing less burden and different psychosocial demographics.
Conclusions: There is a need for interventions to reduce caregivers' unmet needs in the CPwDh. Such interventions should consider differences in sex and living situation to better address individual caregiver needs.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-116Risk assessment in people living with dementia: a systematic review

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Effective risk identification and assessment helps inform personalised care decisions, positive risk management, policy-making and clinical practice in dementia. This mixed-method systematic review identified key components of risk assessment for people with dementia living within the community and care homes, examined attitudes towards risk identification and risk assessment, and appraised existing risk assessment tools. Systematic searches of eight databases and grey literature were conducted. Studies were screened for inclusion based on predetermined eligibility criteria and quality assessed using the Mixed Methods Appraisal Tool. Findings were tabulated and synthesised using thematic synthesis. Twenty studies were included in the review. Five overarching themes emerged from the synthesis: Conceptualisation of risk –how different individuals define, construct, and identify risk situations. Components of risk –key elements included in risk and safety assessments. Contributors to risk –factors that impact the risk level and how risk assessments are conducted. Perspectives on risk assessment –how individuals assess risk and approaches to risk management. Risk reduction –strategies to mitigate risk following an assessment.
Our review found differences in how people with dementia, their family carers, and healthcare professionals conceptualised risk, with views being shaped by media perceptions, personal experiences, sociocultural influences, dementia knowledge and severity. Mobilisation both inside and outside of the home was the most frequently identified risk factor. People with dementia and carers were generally risk-tolerant, while healthcare professionals adopt risk-averse approaches that reflect organisational requirements and ensure safety. Factors that disrupt daily routines, living and caring arrangements, medication management, and unclear care pathways contribute towards adverse risk events. Few studies considered people with dementia's insight into the risk being assessed. Accurate risk assessment and effective communication strategies are needed to enable risk-tolerant practices and ensure these approaches can be evaluated effectively. No instrument to date was shown to be widely acceptable and useful in practice.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-117Risk assessment and increasing safety in dementia – RAISe-dementia study

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UK policy priority is to support people with dementia (PLwD) to live at home for longer. Initial clinical assessment involves evaluating and managing risk to enable PLwD to live safely and well at home. Risk assessment scales are needed to identify, manage and reduce risk within contemporary dementia practice. The "Islington Dementia Navigator Risk Assessment Tool" (INDRAT) is used by specialist and non-specialist staff to stratify the level of risk for PLwD and inform a risk management plan and the frequency of follow-up. We evaluated INDRAT's validity, and the feasibility and acceptability of the resulting risk management plan.
Part 1 assessed whether the risk assessment tool enables risk detection by examining validity- how well INDRAT identifies risks compared to gold standard semi-structured clinical assessments.
Part 2 reviewed whether the risk detection and intervention can be used for the safety of PLwD living at home by examining feasibility- whether careplans derived from the tool were implemented over the subsequent 6-12 months. Acceptability- what PLwD and family carers thought of the process and how it can be improved?
We found that the INDRAT used by non-specialist practitioners (dementia navigators) does enable PLwD to live safely at home in terms of risk-identification, implemented risk enablement decisions and acceptability. Clinical risk assessment and IDNRAT scores showed concordance between clinicians' ratings. Joint Dementia navigator and researcher interviews showed consistency between the different assessor scores demonstrating INDRAT has good reliability. Risk severity ratings (red/amber/green) were observed to reduce over the 6-12 month time period. Participants found the risk assessment acceptable and felt included in decision-making processes. INDRAT is a valid and reliable risk assessment tool offering a tailored approach to the management of risk, and over 80% of careplan decisions were implemented. This is consistent with best practice and the tool has potential for wider use.

Patient pathways - Hospital care

POS1. Posters - Patient pathways

POS1-118Towards a dementia-friendly hospital

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Fondation Médéric Alzheimer

For people living with dementia, the arrival in hospital represents a sudden break in their living environment and a loss of their points of reference. This is a source of anxiety, which can have deleterious consequences on their state of health, especially if the family carer cannot be present. Many health care professionals find themselves in difficulty when confronted with a person living with dementia, due to a lack of training in the specificities of this pathology. Since 2013, the Fondation Médéric Alzheimer provided teams the means to implement projects to improve the reception and care of people living with dementia in hospital, thanks to a financial grant. The projects submitted are examined by a multi-disciplinary jury. This call for projects is carried out in partnership with two french professional federations, to allow wide dissemination. In 2020, a working group initiated by the Fondation led to the publication of a guide "How to improve the care of people living with dementia in emergency departments". We will update this guide and make it available to all hospital departments. It will be based on four main principles: A pathway approach; Training and raising awareness of geriatric culture and dementia among hospital professionals; A suitable environment; The use of psychosocial interventions to facilitate communication and care. These axes will be illustrated by "good practices", and will present existing projects that have proved their worth. The guide will be a useful toolbox for all those wishing to develop an "dementia-Friendly" project within the hospital. The Fondation wants hospitals to become increasingly "dementia-Friendly". It aims to build a community of committed health care professionals through: Promoting initiatives; Turnkey tools for teams; Peer-to-peer feedback and sharing; Multidisciplinary working groups. Based on the recommendations of this community, the "Towards a dementia-friendly hospital" initiative will be launched.

Patient pathways - End-of-life care

POS1. Posters - Patient pathways

POS1-119Reducing eating and drinking related hospital admissions for people living with dementia: an evaluation of a quality improvement programme

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Background: Half of Speech and Language Therapy (SALT) referrals and a third of Admiral Nurse (AN) referrals are for people living with dementia (PLWD) who are experiencing eating and drinking difficulties. Development of a Quality Improvement Programme to include eating and drinking in Advance Care Planning (ACP).
Aims: To reduce hospital admissions for eating and drinking related difficulties and increase numbers of PLWD with an AC. Carer training package to improve knowledge and understanding of eating and drinking issues in dementia
Methods: Audit of hospital admissions for eating and drinking difficulties of people known to both caseloads. Baseline audit of ACP on AN caseload. Repeat audit following carer training programme. Eating and drinking changes in dementia. 1 x 3 hour training session covering feeding strategies in dementia; feeding at risk; end of life eating and drinking changes. Co-delivered by SALT and AN as part of 8 week carer training programme. ACP training: 1 x 3 hour session every 8 weeks, delivered by AN as part of 8 week carer training programme. Results measured for eating / drinking and ACP through evaluation questionnaire at end of every 8 week training programme. Cohorts 1-6 (March 2022 – December 2023).
Results: Majority of hospital admissions came from residential or nursing homes, rather than community admissions. Improvements in eating and drinking knowledge up to 86%. Confidence in dealing with eating and drinking changes went from 21% to 83%. 82% of carers found the training very helpful in planning for the future. Baseline audit was 36% of PLWD on AN caseload with an ACP. Final audit 71% of PLWD with an ACP.
Impact going forward: Eating and drinking training programme for local nursing homes (2024); “Having the [ACP] plan helped when dad went into hospital”
Limitations:
Small sample sizes and small staff numbers to run training.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-12Lifestyle intervention in memory clinics of general and academic hospitals trial (LIGHT): rationale and design of a randomized controlled trial to reduce dementia risk

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Introduction: Dementia risk reduction through lifestyle modification has much potential but is not widely implemented in routine care. Patients referred to memory clinics are at high risk for dementia and tend to have worse health and lifestyle profiles. While they might benefit from lifestyle changes, there is currently no service available to help them make those changes. Methods: Lifestyle Intervention in the memory clinics of General and academic Hospitals Trial (LIGHT) is a 12-month multicentre randomized controlled trial investigating the effects of an innovative lifestyle intervention compared to usual care. Starting in the summer of 2024, the trial aims to include 300 older adults (≥ 50 years) with subjective cognitive decline (SCD) and mild cognitive impairment (MCI) who have ≥2 modifiable dementia risk factors (to ensure room for improvement) primarily from the memory clinics of Maastricht UMC+ and Amsterdam UMC. Participants will be randomized 1:1 to the intervention or usual care with general health advice. The intervention comprises three components: 1) three personal meetings with a certified lifestyle coach to work on personal goals, 2) vouchers for access to brain-healthy activities from local providers, and 3) online-access to a recently developed risk self-management platform (www.breinzorg.nl). The primary outcome will be 'the 12-month change in participants' dementia risk profiles as measured by the 'LIfestyle for BRAin Health' (LIBRA) index. Secondary outcomes include cognitive functioning, health-related quality of life, activities of daily living, psychological measures, and individual lifestyle components. Results: LIGHT will provide insights into the effectiveness, implementability and (cost-) effectiveness of a lifestyle intervention in a clinical setting. Conclusion: LIGHT will provide evidence for a personalized, multidomain lifestyle intervention for indicated prevention of dementia. The ultimate goal is to implement personalized lifestyle coaching in the regular service offered by Dutch memory clinics.

Patient pathways - End-of-life care

POS1. Posters - Patient pathways

POS1-120France Alzheimer's Institute: end-of-life support training

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France Alzheimer et maladies apparentées

Each year, France Alzheimer's Institute trains hundreds of healthcare professionals bringing medical and social support to people living with Alzheimer's or a related disease, at home or in nursing homes. Over the last two years, 7 trainings sessions have already been carried out, dedicated to strenghtening the support of people with dementia at the end of their life. The objective for the Institute is to provide its expertise to professionals and to preserve the quality of life of people with dementia at the end of their life, taking into account the specificities attached to the terminal evolution of Alzheimer's or a related disease. Palliative care of people wAith dementia is no different from that of other patients at the end of life. It is more delicate due to cognitive disorders and in particular almost constant communication disorders in terminal phase. Thus, both pain and depression can express themselves in atypical ways. End-of-life support then requires that healthcare professionals quickly identify their limits when confronted to the suffering and demise of a person living with dementia, in order to mobilize their own internal resources and provide the best support possible. It is essential to adapt to people's specific needs in these situation. Just as special listening and support for bereaved families contributes to improving the quality and the adaptation of care. Currently, the Institue offers a complete training program which allows professionals to adapt their care. It also offers professional caregivers tools to work on their own positioning in the palliative process by integrating ethical dimensions, with support for helping families in their grieving process. End-of-life support is a subject at the heart of concerns and in this context, France Alzheimer's volunteers are trained to listen to people's need and to guide families towards the right solutions and various existing aids.

Patient pathways - End-of-life care

POS1. Posters - Patient pathways

POS1-121Integrated medical, long-term, and end-of-life care model for people living with dementia in Taipei city hospital - linsen Chinese medicine branch

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Background and objective: With the progression of neurodegenerative diseases, end-of-life care has become an inevitable yet crucial aspect that demands early planning and preparation. Our poster reports Taipei City Hospital's strategic approach to integrate dementia care with long-term care and end-of-life care.
Methods: We use the Memory Clinic as a platform to promote dementia-friendly community activities. We regularly conduct health literacy activities for older adults at each community service site. At the daycare center, we provide personalized support for people living with dementia (PLwD) and their caregivers, offering family support and respite care. In the Memory Clinic, we provide integrated case management combining traditional Chinese, medicine and paramedical social psychological services. We also offer PLwD and their caregivers consultations and advanced care planning tailored to each stage of the disease, including end-of-life care planning. We proactively assist PLwD and their caregivers in connecting with community long-term care services and home medical and nursing care services. If a patient enters the advanced stage, they are transitioned to community end-of-life care. Our team members all have undergone training in advance care planning consultation, long-term and palliative care.
Results: As of now, our hospital has diagnosed 634 PLwD cases in the case management care service. Of the 452 PLwD received long-term care evaluation, 56 are graded with mild care needs, 230 are moderately care needs, and 166 are severe care needs (among them 157 cases with complex care needs). In our hospital, 19 clients have already received end-of-life care.
Conclusion: Our integrated model for medical, long-term, and end-of-life care is effective and meets the needs of PLwD and their caregiver throughout their care journey.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-13An online dementia risk self-management platform for memory clinic patients and healthcare professionals: a pilot study of BreinZorg

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Persons with subjective cognitive decline (SCD) or mild cognitive impairment (MCI) face an elevated dementia risk and could benefit from lifestyle-focused preventive interventions. Persons with SCD or MCI also were interested to enhance their brain health independently during our previously conducted needs assessment. Therefore, we developed the online risk self-management platform BreinZorg about dementia risk reduction through lifestyle modifications for usage in clinical practice. We explored attitudes and opinions about the platform among patients and healthcare professionals (HCP) from Dutch memory clinics. We included persons with SCD or MCI and HCP who had expressed interest in this pilot study during our previous needs assessment. We used an adapted version of the Program Participation Questionnaire for in-depth interviews on usability, user-friendliness, and acceptability of the platform. Additionally, think-aloud sessions were held to further explore experienced facilitators and barriers. We conducted 18 interviews with persons with SCD or MCI (n=13) and HCP (n=5). Additionally, 9 think-aloud sessions were held among persons with SCD or MCI (n=6) and HCP (n=3). Information provided by BreinZorg was deemed useful and applicable, although several participants were already partly familiar with its content. However, translating this information into actual behavioural changes proved challenging. Participants perceived the platform to maintain a non-judgmental tone, which was positively received. Tailorizing and personalization of information such as individual lifestyle-profile-based module suggestions and setting personal goals, facilitated usage. Barriers included lack of follow-up on personal goals and guidance in suggested modules, particularly for participants with an unfavourable risk profile (e.g. many themes in their room for lifestyle improvement). BreinZorg was generally considered useful, user-friendly, and acceptable by persons with SCD or MCI and HCP from Dutch memory clinics. Incorporating tailored follow-up on goal setting and streamlining module recommendations, could enhance user engagement. The platform is currently tested in an extended feasibility study.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-14The role of mental health, physical exercise, and metabolic syndrome as mediators of the effect of hearing loss on cognitive performance in the UK Biobank

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Background: Previous research showed that hearing impairment was associated with an increased risk of mild cognitive impairment and an accelerated rate of cognitive decline (Bucholc et al., 2022). However, the mechanism whereby hearing impairment impacts cognition remains unknown and under-researched. Objective: To investigate mediators of the effect of hearing impairment on cognition in the UK Biobank study. Methods: The UK Biobank is a large, population-based study that involved the recruitment of 502,665 participants and the collection of comprehensive baseline data (Sudlow et al., 2015). This project examined the effect of hearing impairment on cognitive performance including executive function and processing speed. Physical exercise, metabolic syndrome and mental health were investigated as mediators. Structural equation models (SEMs) were used to investigate mediators of the effect of hearing impairment on cognition. Results: Hearing loss and metabolic syndrome were independent predictors of lower performance in executive function and processing speed tasks. Physical activity showed a counterintuitive negative effect on executive function with higher levels of physical activity being associated with lower levels of executive function. There was evidence of partial mediation for the effect of hearing loss on executive function by physical activity. However, the path coefficients of the components of the indirect effects are counter-intuitive: hearing loss resulted in more frequent physical activity and more frequent physical activity lowered performance in executive function tasks. The negative effect of hearing impairment on executive function was mediated by mental health-related distress. No evidence of mediation was found for the effect of hearing loss on processing speed. Conclusions: Hearing loss may have a negative impact on mental health which in turn then may lower cognitive performance. Metabolic syndrome is a predictor of cognitive decline but independent of hearing loss.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-15Brain-healthy generations: an intergenerational project to empower young and old for a lifetime of brain health

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Introduction: Most people are not aware of the relationship between lifestyle and brain health. Promoting a brain-healthy lifestyle in the population can reduce the growing number of people with dementia in the future. Dementia risk reduction should ideally start before unhealthy lifestyle patterns become ingrained and difficult to change. Education about brain health should therefore start with our youngest generations: primary school children. However, children's lifestyle choices are highly influenced by their parents' choices. An intergenerational approach where children and (grand)parents work together can tackle this issue. Methods: This project explores an innovative and creative approach to stimulate a brain-healthy lifestyle. Primary school children (10-12 years old) will receive a "braincoach training" in the classroom by the research team, supported by the teacher. Subsequently, children will have an important guiding role in educating and activating the (grand)parents in a fun and playful way. The design, implementation and evaluation are (partly) determined by children and their (grand)parents in a truly participatory approach. Three primary schools will be included in the province of Limburg, the Netherlands. Results: With this project we aim to increase knowledge about and motivation for a brain healthy lifestyle in both children and their (grand)parents and to evaluate the feasibility of this approach for further implementation. Conclusion: This unique project translates research about modifiable dementia risks to society in order to benefit the health of the population and reduce the future burden of dementia. Children educate and guide (grand)parents in healthy living instead of the other way around. It may lead to new approaches in attracting hard-to-reach groups in society. The main deliverable of the project is the availability of a teaching toolbox for schools, including a workshop and script for teachers and out-of-the-box educational materials for children.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-16The association between dual audiovisual sensory impairment and dementia - a systematic review of the literature

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Previous research has suggested that sensory impairment, and more specifically hearing and visual impairment, are independent risk factors for dementia and mild cognitive impairment (MCI). However, more recently, researchers have suggested that dual audio-visual impairment – consisting of the presence of both hearing and visual impairment – may be a more substantial risk factor for dementia and MCI compared to singular sensory impairment. Here, we conducted a systematic review of the literature across three databases to synthesise the literature of dual sensory impairment as a risk for the development of dementia. Apart from a discussion on why dual sensory impairment might be a more substantial risk factor for the development of dementia, the presentation will include a comparison of the use of subjective versus objective measurements of sensory impairment, the quality of studies within the area, as well as recommendations for further studies within the area of cognition, dementia, and sensory impairment.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-17Social health to prevent cognitive decline and dementia: Integration of results from men and mice studies and new avenues to interventions

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Prevention of dementia is considered a healthcare priority. There is an urgent need to find new avenues to prevent dementia. In considering dementia as a multifactorial syndrome, social health is increasingly known to play a role in the development of cognitive decline and dementia. We aim to integrate the results of our SHiMMy (Social Health in Mice and Men) project on social health and cognition and dementia with the goal to identify mechanisms and novel avenues to prevent dementia. We used the social health hypothesis assuming that social health stimulates the use of cognitive reserve, thus slowing down cognitive decline, and generated biology-based hypotheses to guide the specific studies. We integrated the results of the SHiMMY human epidemiological and qualitative studies and the

mouse studies by categorizing them into the conceptual framework for social health. Our epidemiological studies demonstrated associations between social health (marital status, perceived social support, and loneliness) and brain structure (including total brain volume, white matter volume and white matter microstructural integrity). Integrated with the qualitative studies, these findings confirmed the key role of a partner in life as well as the value found in being meaningful within the social environment and reciprocated social support. The rodent study added a biological substrate for the relationship between social health and cognitive functioning by showing genetic and neurobiological overlap for the cognitive and social domains. Integrating our results into the social health conceptual framework revealed social health markers representing potential targets for intervention. The main conclusions of rodent and human studies are in line with each other, showing that social health matters to brain health. The identified targets (i.e reciprocated social support) for interventions can be applied in daily social interaction, public health and clinical settings and stress the need to focus on social health in dementia prevention efforts.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-18Effective brain health promotion and memory disorder prevention through collaboration

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Suomenselän Muisti ry

Background: It is estimated that by 2024, there will be 247,000 people with a memory disorder in Finland, if the age group-specific mortality remains unchanged. (Roitto et al. 2024) The Finnish FINGER intervention study was the first in the world to show that acting on five different lifestyle factors at the same time can improve and maintain cognitive function in older people at risk of developing a memory disorder (Ngandu et al. 2015). Goals: The goal of MuistiTerve-Pohjois-Suomi 2023–2025 project working on improving cognitive health in Northern Finland is to collaborate on developing and instilling the FINGER lifestyle programme together with wellbeing services counties and municipalitie Methods: Wellbeing services counties and municipalities have been involved in the development of the lifestyle programme and customer path that follows the FINGER model, and in the implementation of pilot groups since the beginning. Results: Three welfare services counties in Northern Finland and six municipal sports operators are committed to co-developing and implementing the operating model as part of primary health care services.

Conclusions: The collaborative model works in real collaboration with health and sports professionals across sectors. Collaboration enables a multi-professional long-term group entity that increases social well-being and reduces loneliness. The collaboration model we have developed provides a tool for promoting brain health and preventing memory disorders nationwide.
Keywords: lifestyle guidance, collaboration, FINGER, brain health, memory health;
Sources:
Ngandu, T. ym. 2015. A 2 year multidomain intervention of diet, exercise, cognitive training, and vascular risk monitoring versus control to prevent cognitive decline in at-risk elderly peo-ple (FINGER): a randomised controlled trial. The Lancet. (385), 2255–2263, DOI: https://doi.org/10.1016/S0140-6736(15)60461-5; Roitto, H-M., Lindell, E., Koskinen, S., Sarnola, K., Koponen, P & Ngandu, T. 2024. Diagnosoitujen muistisairauksien ilmaantuvuus ja esiintyvyys Suomessa vuosina 2016–2021. Medical Journal Duodecim 2024;140(5):411–9 https://www.duodecimlehti.fi/lehti/2024/5/duo18137

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-19Assessing the effects of physical activity interventions on the maintenance of midlife cognitive function to reduce the risk of cognitive decline: a systematic review

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Introduction: Risk reduction is an important area of research providing opportunity to substantially reduce future dementia incidence by promoting brain healthy lifestyles. Efforts focussing on midlife (45-65 years old) as a window of opportunity to promote healthier lifestyles, have the potential to improve general health as we age. Physical inactivity is one of twelve identified modifiable risk factors. There is some evidence to suggest that lower levels of physical activity are associated with increased dementia risk. We do not know levels of frequency, intensity, duration and adherence of physical activity required to exploit an effect in terms of dementia prevention. Gaps in the evidence remain regarding how to maximise the development and delivery of activity/exercise interventions, and how to

improve uptake and long-term adherence. Methods: MEDLINE, the Cochrane central register of controlled trials (CENTRAL), Embase, PsycINFO, and CINAHL electronic databases were searched, all available years up to February 2024 in English only. Inclusion criteria were cognitively healthy, mid-life adults (45-65 years old). Randomised Controlled Trials of physical activity as the only intervention, that had a minimum follow-up of 26 weeks were included. PROSPERO registration: CRD42023492462; Results: Some 5000 records were screened by title and abstract by five independent reviewers. Full text screening of 271 potentially relevant records is underway. This systematic review is ongoing and comprehensive findings will be reported in Autumn 2024. Initial review findings suggest that small sample sizes, short intervention and follow-up periods compromise quality of evidence. Nevertheless, some encouraging evidence does exist regarding physical activity as potentially important in the promotion of brain health.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-20Association between the “lifestyle for brain health (LIBRA)” score and incident stroke: a 25-year follow up of the Maastricht aging study (MAAS)

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Background: The LIBRA score was developed and extensively validated as a tool to identify an individual’s rooms for lifestyle improvements regarding dementia risk reduction. The LIBRA score was originally composed of twelve modifiable risk and protective factors for dementia and was recently updated with three new factors (LIBRA2). A higher score (representing an unhealthier lifestyle) has been associated with increased risk of cognitive decline, dementia and brain MRI abnormalities. Whether the score also predicts risk for other brain disorders is unknown. The current study therefore assessed whether a higher LIBRA score is associated with incident stroke. Methods: We used data from 1,410 participants of the Maastricht Aging Study (MAAS) followed up for up to 25 years. Baseline information was available for fourteen LIBRA2 factors (excluding healthy diet). Cox proportional hazards regression, adjusted for age, sex, and education, was used to investigate the association between (variations of) the LIBRA score and stroke risk. Discriminatory performance was determined using the Harrell’s C index (C-statistic). Results: During a

mean follow-up time of 17.5 years, 56 individuals developed a stroke (3.9%). A one-point increase in LIBRA and LIBRA2 was associated with a hazard ratio of 1.05 (95% CI, 0.92-1.20) and 1.02 (95% CI, 0.95-1.10), respectively. The discriminatory performance was better for the model using LIBRA2 (C-statistic = 0.60) as opposed to LIBRA (C-statistic = 0.53). In a sensitivity analysis, we found a higher hazard ratio (1.11; 95% CI, 0.90-1.37) and discriminatory power (C-statistic = 0.67) for a modified LIRBA version only including cardiometabolic factors (low-to-moderate alcohol consumption, physical inactivity, diabetes, hypercholesterolemia, smoking, obesity, hypertension) Conclusion: LIBRA and LIBRA2 were not significantly associated with stroke risk, but numbers of incident stroke were low. Studies with larger sample sizes are warranted to determine whether LIBRA(2) could be used for identifying individuals at higher risk of stroke.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-21Development of a community-based intervention for inclusive dementia risk reduction: lessons learned from the Netherlands dementia prevention initiative (NDPI)

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Background: A substantial proportion of dementia cases is likely attributable to modifiable risk factors, with risks being distributed unequally in the population. People with low socio-economic status or migration background, for example, have a higher dementia risk. However, they are often underrepresented in dementia research and prevention programs. As part of the national Netherlands Dementia Prevention Initiative (NDPI), a population-based awareness campaign on brain health and dementia risk reduction is being (further) developed, including a targeted community-based participatory campaign approach in disadvantaged neighborhoods. Methods: NDPI comprises five projects, including the INFORM project aimed at developing a public health intervention in co-creation with the target groups (e.g., through focus group interviews) and participatory action research at the neighborhood level. The 12-months awareness campaign will run in 2025. Results: Several face-to-face and online focus groups with people with a lower socio-economic position or a migration background were organized to learn about their needs, wishes and barriers for

engaging in brain-healthy behaviours, preferences in communication and for providing feedback on developed materials. A participatory action research approach is currently implemented to reach, engage, and communicate within this diverse population. Community-based process evaluation will provide essential insights in the facilitators and barriers for large-scale implementation of dementia risk reduction initiatives. By measuring the awareness before and after the campaign, knowledge will be gained on whether population-based interventions are effective for increasing awareness and improving modifiable dementia risk profiles. Conclusion: Engagement of underrepresented target groups is invaluable for developing interventions aimed at raising awareness on dementia and brain health as they have the most room for improvement. This is indispensable for reaching the goal of inclusive dementia risk reduction and closing the brain health gap.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-22Longitudinal population-attributable fraction of chronic conditions for the risk of dementia

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Background: Multimorbidity is associated with increased dementia risk and the number of chronic conditions in people living with dementia accelerates at a higher pace starting two decades before the onset of clinical symptoms. However, estimation of the total contribution of multimorbidity to dementia incidence requires to account for heterogeneity in combinations and timely sequences of chronic conditions. We estimated the absolute contribution of eight risk factors to Alzheimer's disease and related dementias (ADRD), with the longitudinal extension of the average attributable fraction (LE-AAF). Method: We analyzed claims from 9,994 Medicare fee-for-service beneficiaries that participated in the Health and Retirement study between 1998-2016. Participants were between 68 and 99 years of age, had no ADRD at baseline, and were censored after the first year with missing claims. Results: Hypertension, acute myocardial infarction, atrial fibrillation, diabetes, heart failure, ischemic heart disease, arthritis, and stroke additively accounted for 71.8% (95% BCA CI, 62.9%-79.1%) of ADRD cases, with hypertension as strongest contributor. Acute myocardial infarction did not significantly contribute to ADRD incidence. Discussion: Our findings suggest that multimorbidity plays a pivotal role for explaining ADRD incidence in

the US. Targeting constituents of a cardiovascular path to dementia may contribute most to lowering dementia risk. The findings corroborate in a large observational study earlier evidence on the importance of managing hypertension to reduce risk of dementia, for which effective treatments exist and are comparatively easy to administer at scale. Potential to dementia prevention may be even greater than previously estimated.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-23Can a new dialogue concept ("CST Health") for Danes with increased dementia risk engage them in a lifestyle intervention? development and pilot test

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Aim: This study aims to develop and test an engaging dialogue group programme ("CST Health", CH) to increase knowledge and individual commitment to healthy lifestyles in people with increased dementia risk. Background: Dementia risk can be reduced by complex lifestyle interventions. However, long term maintenance of healthy lifestyle changes is challenging. Professional support often includes personalized health advice. Inspired by successful group sessions with Cognitive Stimulation Therapy (CST) to people with mild dementia (Spector, 2003), this study will develop and test an equal and fun dialogue concept, CH. CST-based group sessions with focus on healthy lifestyles are developed to support knowledge, coping, cognition, and behavior change in people with increased dementia risk. The study is part of the larger Danish research study “PreventDementia”. Methods: Spring 2024, five CH-sessions were developed at VIA University College, by a team of specialists within healthy aging in collaboration with a municipal occupational therapist with CST skills. The themes focus on coping with everyday activities and cognition, behavior change, physical activity, healthy nutrition, and risk factors. In May-June 2024, eight participants (6M, 2F; 63-84 yrs) newly diagnosed with Mild Cognitive Impairment were recruited from a 4-month exercise and cognitive programme in Aarhus Municipality. The 75-minutes CH-sessions will be held at “DemensHjørnet” once weekly, facilitated by the CST specialist. Data collection: The experimental part starts May 2024. By questionnaire and interviews, sessions will be evaluated focusing on group dynamics, educational value, cognitive stimulation potential, adherence, and individually perceived

meaningfulness. Results will be presented. Conclusion: By positive results, the CH-sessions will be further qualified. CH will then be integrated into a 3-month complex (pilot) lifestyle intervention for people with increased dementia risk, in 2-4 Danish municipalities. CH`s potential for contributing to health behavior change and cognitive stimulation will be studied in more detail.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-24Mediating factors associated with physical activity in older adults at increased dementia risk

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Objectives: While regular physical activity (PA) is beneficial in many ways, PA engagement tends to decline with age. Particularly, multimorbid individuals at increased dementia risk are likelier to present reduced PA levels than healthy older adults. Thus, the increasing evidence of adverse health consequences of sedentary behaviour in multimorbid patients emphasizes the need for more comprehensive understanding of mediating factors responsible for inactivity in this population. The study aimed to identify mediating factors associated with changes in regular PA in a randomized trial of a multimodal intervention against cognitive decline in an older adult at-risk sample. Method: We analysed data from individuals who completed baseline and follow-up assessments to track changes in PA engagement. A decision tree analysis was conducted to identify mediating factors associated with changes in PA after trial participation at 24-month follow-up. Results: The difference in self-efficacy scores between baseline and follow-up was the most influential factor associated with changes in regular PA ($p<.001$). Additional mediating factors, such as male gender, type 2 diabetes, low social support, intermediate/low education, and higher alcohol consumption, showed a decreased likelihood of adopting PA habits alongside low self-efficacy. Discussion: Interventions that enhance self-efficacy are more likely to promote regular PA. Individualizing interventions, particularly for men, individuals with type 2 diabetes, those with low social support, and those with intermediate/low education and higher alcohol consumption, are important to continue to promote PA among individuals with multimorbidity and at increased dementia risk. Decision tree analysis helps identify high-risk subgroups and improves intervention targeting.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-25Is a long-term postexercise cognitive benefit dependent on improved cardiovascular fitness? an investigation using passive exercise (planned research)

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Dementia is a leading cause of death worldwide. Although current treatments largely address symptoms of disease that can lead to dementia, its onset may be prevented by identifying and modifying relevant life-style risk factors. Regular exercise has emerged as a means to support brain health in individuals with dementia and demonstrates the potential to prevent dementia onset. As well, exercise is effective at slowing cognitive decline, improving cognition, brain health and function, and significantly reduces population-attributable risk for all-cause mortality. Some individuals, however, may not be able to complete active exercise due to cognitive and/or physical limitations (e.g., spinal cord injury, stroke). A potential alternative to an “active” exercise intervention is passive exercise. Passive exercise involves involuntary movement of the limbs via an external mechanical force. Although the benefits of traditional exercise manipulations are numerous and well understood, the extent to which passive exercise benefits cognitive function is currently unknown. Our goal is to therefore understand whether passive exercise supports brain health in a manner similar to traditional exercise. Accordingly, 126 healthy but sedentary older adults (age≥60 years) will be randomly separated equally into stretching and toning, passive exercise, or light-intensity active exercise groups. Participants will undergo baseline cognitive (i.e., executive function battery) and structural and functional (i.e., MRI) brain assessments. They will then be asked to perform their assigned protocol at home 3

times a week for 6 months prior to repeating their baseline assessments after 6, 12, and 18 months. We hypothesise that passive and active exercise will improve executive function in older people, but will induce modality-specific alterations to functional connectivity and structural integrity. As well, changes associated with passive exercise should persist for a timeframe equivalent to, or less than, that of active exercise. These results will support additional longitudinal studies involving other, chronically ill populations.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-26Brain health services for the prevention of dementia: optimal patient journey and pilot experiences

Federica Ribaldi, Giovanni B Frisoni, the European Task Force for Dementia Brain Health Services

The European Task Force for Brain Health Services for the prevention of dementia (dBHS) designed the concept of evidence-based and ethical secondary prevention of dementia in persons with intact cognition at high risk. dBHS have four missions: risk assessment, risk communication, personalized risk reduction, cognitive enhancement. Recommendations for implementing the four pillars have been published, and pilot BHS projects are underway in Stokholm, Scotland, Geneva, Amsterdam, Monza, Barcelona, Cologne, Paris, and New York. The lessons that are being learned thanks to such pilot experiences will allow progressing towards clinical deployment. Certain activities have transitioned into clinical practice, while others remain confined to research projects due to high costs, limited feasibility, or insufficient evidence. Risk assessment addresses 12-lifestyle risk factors, APOEe4, Alzheimer's pathology (amyloid, tau), neurodegeneration and cerebrovascular disease (on MRI), the first two are increasingly integrated into clinical settings, while biological risk assessments largely depend on research projects. Risk communication should include visual aids explained in plain language, ideally through digital tools, although this is currently limited to research projects. Conversely, in-person, semi-structured disclosure of dementia risks is now common in academic memory clinics. The clinical applicability of lifestyle risk reduction is limited by high costs and need for specialized personnel. Initiatives such as MET-FINGER and Geneva's multidomain biological intervention (multivitamin, melatonin, Souvenaid, probiotics), are moving forward, still in the research stage. Cognitive enhancement includes non-invasive brain stimulation (NIBS) and cognitive training, and it is still in early stages of development. The evidence for cognitive training is growing, whereas

NIBS techniques require more research evidence before its clinical implementation. More research, technological development, and resource allocation are required to successfully integrate an optimal dBHS patient journey into clinical practice. The development and widespread adoption of dBHS will help fight dementia and reduce the burden on patients, their families, and society.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-27Cognitive reserve: a protective factor for brain health and prevention of dementia-like disorders

Giulia Marselli, Ilaria Corbo, Francesca Favieri, Giuseppe Forte, Angela Guarino, Maria Casagrande

The prevention and treatment of dementia is one of the most important challenges of our time. The possibility of a connection between life experiences and the development of dementia represents an important field of research. In this domain, cognitive reserve (CR) represents a factor that should be considered to promote a healthy aging pathway and reduce the risk of developing clinical pictures typical of pathological aging, such as mild cognitive impairment (MCI) and dementia. Indeed, the brain changes occurring with dementia may begin before the onset of overt symptoms and are usually expressed by the MCI phenotype. The cognitive degeneration that characterizes MCI is worse than expected in typical aging but less pervasive than full-blown dementia. In this frame, it is hypothesized that one of the protective factors against the neurotypical outcome of dementia is CR. In its most recent definition, CR has been described as a brain attribute enabling higher cognitive abilities despite significant brain changes, injuries, or diseases. Accordingly, the present study aimed to analyze the differences in CR between healthy adults and patients with MCI. Specifically, it is hypothesized that healthy older adults have higher CR than patients with MCI. Two hundred forty-three adults were classified into three groups: healthy controls (HC), amnestic MCI (aMCI), and non-amnestic MCI (naMCI). The Cognitive Reserve Index questionnaire (CRIq) was administered to assess the level of CR. Results showed that HC had significantly higher CR scores than participants diagnosed with aMCI and naMCI. Moreover, binomial logistic regression suggested that low CR was a significant risk factor for the MCI diagnosis. Conclusion: The clinical picture emerging from the results showed that lower CR could be considered a characteristic of pathological aging. Therefore, as an indirect expression of brain reserve, CR may be both a marker and a predictor of adaptive aging.

Patient pathways - Brain health and prevention

POS1. Posters - Patient pathways

POS1-28An online platform for self-education and self-management of dementia risk reduction: a feasibility study among persons with subjective and mild cognitive impairment

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Background: Persons with subjective cognitive decline (SCD) and mild cognitive impairment (MCI) are at increased risk to develop dementia and may benefit from secondary prevention through lifestyle interventions. Despite an expressed interest to receive this information, dementia risk reduction is not regularly discussed during consultations at the memory clinic. Providing this group with educational material about dementia risk reduction might increase awareness, self-efficacy and promote behavioural changes. Within the Dutch ABOARD consortium, the online platform BreinZorg for self-management of dementia risk reduction through lifestyle modification has been developed through co-creation. The current study aims to investigate feasibility, user experience, and preliminary effectiveness of this platform in persons with SCD and MCI. Methods: This is a single-arm, mixed-method feasibility study with a hybrid effectiveness-implementation design in 60 persons recently diagnosed with SCD or MCI from 5 Dutch memory clinics. After an initial in-person meeting, participants will use the platform for 3 months. The platform contains layered information on 16 modifiable risk and protective factors for dementia. Implementation outcomes focus on acceptability and feasibility, using data on usability and qualitative data from interviews. Effectiveness outcomes include questionnaires on self-efficacy, feeling of control, motivation to change, awareness and behaviour. Results: Recruitment started in April 2024. Design of the current study, baseline characteristics (e.g., age, sex, education) and baseline effectiveness outcomes (e.g., self-efficacy, motivation, awareness) will be presented at the conference. Discussion: In memory clinics, there often is insufficient time to educate persons about modifiable dementia risk factors and help them make changes to reduce these risks. This online risk self-management platform BreinZorg aims to fill this gap. Current study will inform about the feasibility, usability, and experiences of this new platform by persons with SCD and MCI. Findings will further guide adaptions and implementation of BreinZorg in memory clinics throughout the Netherlands.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-29A systematic review on the evidence of misdiagnosis in dementia and its impact on accessing dementia care

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Background: There is a drive to increase diagnosis rates in dementia, whilst a lack of attention is being paid to getting a correct timely diagnosis. For people with a rarer subtype of dementia, getting the correct diagnosis, and subsequent care, might be more difficult than for people aged 65+ presenting with symptoms of Alzheimer's disease dementia, the most common subtype. rarer subtypes of dementia include Lewy Body, Parkinson's, vascular, behavioural-variant frontotemporal dementia, and posterior cortical atrophy, amongst others. Thus, the aim of this mixed-method systematic review conducted as part of the INTERDEM Taskforce on inequalities was to synthesise the evidence base on misdiagnosis of dementia. Methods: Misdiagnosis in dementia comprised of either receiving the incorrect dementia subtype diagnosis at first or receiving an incorrect non-dementia diagnosis. Post-mortem assessments of subtype diagnosis were excluded. Nine data bases were searched, with each title and abstract and full text screened by two researchers. Results: Twenty studies were included. Studies were categorised into four themes: (i) Factors associated with delayed diagnosis or misdiagnosis; (ii) Difficulties related to the diagnostic process; (iii) Economic consequences of misdiagnosis; and (iv) Experiences of delayed diagnosis or help-seeking. People with Lewy Body dementia or behavioural variant fronto-temporal dementia were found to experience longer diagnosis times and often incorrect initial diagnoses. Overall limited evidence exists however on individual dementia subtypes, with a lack of evidence on the experiences of people with dementia and their carers of the diagnostic process. Whilst evidence is limited regarding the economic impacts, evidence from the US points towards increased economic costs of misdiagnosis. Conclusions: Research needs to investigate the rates of different dementia subtype misdiagnosis, alongside their emotional and economic impacts on people with dementia, their carers, and the health care system. Advancing the evidence base is crucial to reduce misdiagnosis and inform clinical practice.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-30Does providing the delirium triage screen to elderly patients in the emergency department enable early detection of geriatric delirium?

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In our regional hospital's emergency department, age is recognized as a major risk factor for delirium. Elderly patients often show unusual behavior when seeking medical care, prompting questions from family members or healthcare colleagues about acute delirium. To address this, we proposed using the Delirium Triage Screen (DTS) for early detection. It's worth noting that patients aged 65 and above make up over 28% of our emergency department visits. After discussions among healthcare professionals, we posed the question: Can the DTS effectively identify delirium in older adults? Using the Evidence-Based Practice framework, we formulated a PICO question: P: Emergency Elder Patients, I: Delirium Triage Screen, C: Standard nursing care, O: Early detection of acute confusional state. We searched using English keywords and synonyms, with Mesh terms like Emergency, Delirium Triage Screen, and Acute Confusional State. Our strategy employed Boolean logic with OR connectors and AND intersections, limiting articles to those published within the last 10 years, including cohorts, RCTs, and SRs, focusing on emergency patients aged 65 and above. The search yielded 8 PubMed articles, with none from CINAHL or Cochrane, totaling 8 articles. One article was relevant and underwent NOS assessment, resulting in a Level 2 classification. This article reviewed 117 studies, revealing the DTS's limited specificity at 55% (95% CI 50–60%). Positive screenings required further external assessment. From January to March 2024, our emergency department assessed 320 elderly patients aged 65 and above, identifying 35 with positive DTS results, facilitating early intervention for delirium care. References: Lee S, Gottlieb M, Mulhausen P, Wilbur J, Reisinger HS, Han JH, Carnahan R. Recognition, prevention, and treatment of delirium in emergency department: An evidence-based narrative review. Am J Emerg Med. 2020 Feb;38(2):349-357. doi: 10.1016/j.ajem.2019.158454. Epub 2019 Oct 8. PMID: 31759779.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-31Accuracy of the montreal cognitive assessment and mini mental state examination in detecting mild cognitive impairment in a cohort of people with cognitive complaints

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Background: Comprehensive neuropsychological assessments remain the gold standard for diagnosing cognitive deficits. Nevertheless, cognitive screening instruments continue to be widely used in clinical practice since neuropsychological assessments are often inaccessible. We aim to compare the accuracy in detecting mild cognitive impairment (MCI) of the Montreal Cognitive Assessment (MoCA) and Mini Mental Status Examination (MMSE) with a comprehensive neuropsychological assessment. Methods: Participants enrolled in the "programme dementia prevention" (pdp) who completed MMSE, MoCA, and a neuropsychological test battery were selected for this study. For the detailed neuropsychological assessment, containing standardised tools evaluating different cognitive functions, MCI was classified when obtaining at least one test result with a z-score < -1.5 or more than two test results with z-scores < -1.0. For MoCA and MMSE standard cut-offs were applied. Results: 583 participants (mean age = 68.47 ± 11.4) qualified for data analysis (MCI = 499, subjective cognitive decline (SCD) = 59, dementia suspicion = 25). For MCI, a sensitivity of 0.525 was reached for MoCA and 0.086 for MMSE. The specificity was 0.905 for MoCA and 0.917 for MMSE. MoCA outperformed the MMSE in detecting MCI (AUC = 0.715 vs. 0.501). The simulated ROC-curve-analysis identified optimal ranges for MCI for MoCA (17.5-26.5 points) and MMSE (21.5-28.5 points). Conclusion: Our study illustrates how the measured cognitive status of subjects can vary depending on the choice of applied tools. The results are consistent with other studies showcasing the superiority of MoCA compared to MMSE as a screening tool, which is why a continued MMSE usage is questionable. The use of appropriate assessment tools is crucial in reducing subject enrolment biases and will become increasingly important for the early identification of target subjects for future pharmaceutical interventions. Furthermore, correct classification provides guidance for healthcare decision making and reliable data for training algorithms on dementia risk.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-32Predicting progression to AD and MCI through MRI features, demographic factors, and self-reported cognitive decline

Rachana Tank, Rachel Nosheny

Aims: This study investigates the value of baseline MRI and subjective cognitive decline (SCD) scores to predict MCI and AD progression in cognitively unimpaired (CU) older adults. We hypothesize baseline MRI and SCD metrics associate with future clinical progression. These metrics may improve upon more traditional approaches to population screening. Methods: Participants from ADNI were CU at baseline (n=518). SCD was measured by self-reported Everyday Cognition (ECog) Score, assessing changes in ability to perform daily tasks. Baseline variables, chosen based on evidenced associations with progression, were obtained within 6 months of first ECog score, including: age, gender, education, APOE4 status, amyloid PET, MRI measures (microbleeds, white matter hyperintensity (WMH) z scores, hippocampal volumes), depressive symptoms (Geriatric Depression Scale), self-reported hypertension,
diabetes, and smoking. Individuals were dichotomised into non-progressors (n=432) and progressors to a
clinical diagnosis of Mild Cognitive Impairment or Alzheimer's Disease (MCI or AD; n=86). Logistic regressions examined relationships between predictors and clinical progression. Results: Age, APOE4, time in study, microbleed count and WMH were separately associated with greater odds of progression in univariate models. In multiple regression, male gender (OR = 3.26), SCD (OR = 3.66), smoking (OR = 1.86), amyloid positivity (OR = 5.01), and depressive symptoms (OR = 0.06) associated with clinical progression (AUC = 0.85). Conclusions: Baseline microbleed count and WMH in CU individuals was associated with future progression when tested separately, but were no longer associated when including all predictors, suggesting associations of MRI metrics with future progression may be influenced by other factors. Self-reported ECog was associated with future progression in all models, highlighting the potential value of understudied scalable SCD assessments. SCD showed value in improving future decline prediction alongside evidenced predictors, baseline MRI features did not.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-33The role of cognitive flexibility on higher level executive functions in older adults with mild cognitive impairment and healthy older adults

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Mild Cognitive Impairment (MCI) is a preclinical condition between healthy and pathological aging. It is characterized by a decline in cognitive functions that can involve executive functions (EFs), including cognitive flexibility (CF). According to Diamond's model, CF is a core executive function, along with working memory and inhibition. However, it requires the development of these latter EFs to reach its full potential. In this model, planning and fluid intelligence are considered higher-level EFs. Given the central role of CF in enabling individuals to adapt their daily life behavior efficiently, this study aims to gain valuable insight into the functionality of CF in a preclinical form of cognitive decline. This has been achieved by investigating its role as well as the role of its components, set-shifting and switching, in MCI. The following hypotheses have been tested: (i) healthy participants are expected to perform better than those with MCI on CF and higher-level EFs tasks, taking into account the mediating role of global cognitive functioning; (ii) CF can predict performance on higher-level EFs (i.e., planning and fluid intelligence) tasks differently in healthy individuals and those diagnosed with MCI. Ninety participants were selected and divided into a healthy control group (N=45; mean age 64.1) and an MCI group (N=45; mean age 65.2). All participants underwent an assessment of CF, fluid intelligence, planning, and global cognitive functioning using standardized tasks. The results indicated that individuals with MCI showed greater impairment in global cognitive functioning and EFs performance. Furthermore, the study confirmed the predictive role of CF for higher-level EFs in individuals with MCI and only partially in healthy older adults. From a preventive perspective, this finding is important because by targeting CF, we can improve the enactment of EFs, which is critical for daily living activities essential for successful aging.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-34Multifaceted EEG protocol for comprehensive assessment of Alzheimer's disease progression during emotional processing, working memory and attention: the PREDICTOM study

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Background: Recent scientific evidence highlights that subtle changes in EEG could be used as potential prognostic indicator for Alzheimer's disease (AD) progression and its preclinical stages. The PREDICTOM study aims to develop a comprehensive EEG protocol for early detection in primary care of AD.
Methods: The protocol will involve four tasks administered using a portable EEG solution, lasting approximately 1 hour: a) Resting State (RS): Participants will undergo a ten-minute resting EEG activity in order to assess general cognitive function, b) Wisconsin Card Sorting Test (WCST): participants will have to match the target card to one of the three reference cards based on a hidden rule in order to assess working memory, abstract reasoning and executive functions, c) Ekman faces task (EF): Participants will view facial stimuli displaying emotional expressions in order to examine their emotional processing and perception and d) Two-tone oddball task (TTOP): Participants will undergo an auditory oddball paradigm to assess attentional switching and working memory. EEG recordings obtained during these tasks will assess markers associated with AD progression and functional connectivity in a diverse participant cohort comprising healthy controls, preclinical AD and prodromal AD.
Results: Expected results will indicate potential classification of the groups showing differences in EEG patterns and connectivity, highlighting the potential of EEG as a noninvasive biomarker for AD progression that can be deployed in routine clinical practice. The protocol's comprehensive approach will enable the investigation of various cognitive domains, providing insights into early disease mechanisms and facilitating timely interventions.
Conclusion: The PREDICTOM study's EEG protocol holds promise for improving early detection and monitoring of AD progression. By implementing EEG-based assessments in routine clinical practice our aim is to enhance diagnostic accuracy in the earlier stages of the disease and enable timely and targeted interventions in individuals at risk of AD.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-35The diagnostic and prognostic value of the digit span test among the cognitive spectrum ranging from subjective cognitive decline to dementia

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Background. The Digit Span Test (DST), which is part of the Wechsler Adult Intelligence Scale IV, is commonly used in clinical settings, including for the assessment of cognitive disorders and dementia. The DST primarily measures working memory and attention. Aims. This study investiagted the difference in DST and its subtests between people with subjective cognitive decline (SCD), mild cognitive impairment (MCI), and dementia. Furthermore, the predictive value of the DST for the development of dementia in people with SCD and MCI was evaluated. Method. The study included 453 participants from the BioBank Alzheimer Center Limburg (BBACL) (SCD N=189, MCI N=190, and dementia N=73). The DST's discriminative value was analyzed using Analysis of Covariance, adjusted for age and depressive symptoms, while its predictive ability was assessed through logistic regression analyses and Area Under the Curve statistics. Results. The DST scores, adjusted for age, and Geriatric Depression Scale-15 (GDS) total score, indicated that all variables significantly differed among the groups ($p < 0.001$) and thus had good discriminative power. The DST total exhibits robust predictive power across cognitive states (AUC=0.70, $p<0.01$). Notably, the backward span score (OR:0.687, 95%CI:0.516–0.916, $p<0.05$), sequencing span score (OR:0.713, 95%CI:0.567–0.897, $p<0.01$), and total score (OR: 0.828, 95% CI: 0.732–0.935, $p<0.01$) all demonstrated significant predictive capacity for the progression to dementia. Conclusion. In summary, the DST subtests significantly differed between stages of cognitive decline. The backward and sequencing subtests, in particular, showed significant predictive value for dementia progression and are therefore of value in the early diagnostics in a memory clinic setting.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-36Test-retest reliability of a motor-cognitive mobility task in older adults with perceived memory impairment

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Background: It is vital to identify early signs of cognitive impairment and dementia to enable preventive treatment. The Uppsala-Dalarna Dementia Gait project has demonstrated that an established mobility task, complemented with two different verbal tasks, can discriminate between individuals with different cognitive ability and predict conversion to dementia. The aim of this study was to establish the robustness of these test outcomes by investigating the reliability of the motor-cognitive task in individuals with perceived cognitive impairment. Methods: Thirty-four adults with perceived cognitive impairment (18 women, mean age:76, SD:8.9; mean MMSE score:27.1, SD:2.6) performed the Timed Up & Go (TUG), a clinical test entailing rising from a standard chair with armrests, walking three meters, turning 180°, walking back and sitting down. Three TUG conditions were assessed 5-10 days apart: (1) TUG; (2) TUG while reciting names of animals (TUGdt-NA); and (3) TUG while reciting months in reversed order (TUGdt-MB). Outcomes included the time to complete each condition and the number of correctly recited animals and months per 10 seconds. Intraclass correlations (ICC 2.1) and minimal detectable change (MDC) were analysed for each outcome. Results: The results indicated excellent reliability for time to complete TUG, TUGdt-NA, TUGdt-MB, and number of correctly recited months per 10 seconds (ICC≥ 0.94, 95% CI [≥0.87, ≤0.98]). However, the ICC was lower for the number of correctly recited animals per 10 seconds (ICC=0.80, 95% CI [0.59, 0.90]). The MDC results for time to complete each TUG condition were: TUG: MDC=4.9; TUGdt-NA: MDC=5.8; and TUGdt-MB: MDC=6.5. For the number of correctly recited animals/months per 10 seconds the MDCs were 3.8/2.2 respectively. Conclusion: The results indicate that TUG and the TUGdt conditions provide reliable results in individuals with perceived cognitive impairment and support their use in clinical practice for identification of cognitive impairment.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-37Relation of the kynurenine pathway with cognitive functioning and differences in patients with cognitive impairment or dementia: a systematic review and meta-analysis

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Studies suggest that the kynurenine pathway (KP) is involved in pathophysiological processes associated with dementia. However, as clinical studies reported contradictory results and often did not adjust for important confounders, the role of the KP in dementia remains largely unclear. Therefore, the aim of this systematic review and meta-analysis was to summarize the available evidence for i) differences in KP metabolites in patients with cognitive impairment compared to cognitively healthy individuals and ii) associations of KP metabolites with cognitive functioning. English, full length articles published in Pubmed, Embase, PsychINFO, or the Cochrane Database of Systematic Reviews with a prospective, cross-sectional, or case-control study design, up to October 2023, were included. A random effect meta-analysis of standardized mean differences (SMD) was performed. Heterogeneity, meta-regression, small study bias, and study quality assessments were carried out. 8795 studies were retrieved. Preliminary results from 25 studies included in meta-analyses comparing patients with Alzheimer's disease (AD) dementia with cognitively healthy controls indicated lower blood levels of tryptophan (SMD = -0.39 [95% CI -0.52, -0.25]), kynurenic acid (-0.49 [-0.67, -0.31]), and xanthurenic acid (-0.40 [-0.61, -0.19]) in AD. Overall quinolinic acid levels displayed a tendency towards lower levels in AD, but this difference did not reach statistical significance. Associations with cognitive test scores were inconclusive and generally non-significant. These preliminary results suggest that AD dementia is associated with lower blood levels of several KP metabolites and challenges current assumptions of higher quinolinic acid levels to be associated with dementia.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-38Communicating about dementia; how to effectively communicate neuropsychological test results?

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Background: Neuropsychological assessments (NPAs) are imperative for the diagnostic process of neurodegenerative diseases. NPAs provide important insights into the strengths and weaknesses of patients' cognitive profiles, behaviours, and activities of daily living. The communication of NPA results during diagnostic disclosure varies in form and in content. Further, clear communication is challenging due to the (increasing) complexity of information gained from an NPA. Since NPA disclosure can have important implications for disease acceptance, an effective communication strategy to patients and caregivers is important. Therefore, the aim of this study is to gain insight into clinicians' perspective on how they communicate NPA results to patients and caregivers, and how this communication can be improved. Method: During the summer of 2024, five focus groups are conducted with 6-8 participants per group. Participants have experience with diagnostics in Dutch memory clinic settings (academic and non-academic). Two focus groups include physicians (geriatricians, neurologists, etc.) and two groups include psychologists (clinical (neuro)psychologists, healthcare psychologists). The fifth focus group include psychologists

and physicians who participated in previous focus groups. We will investigate what clinicians disclose about the NPA, when they disclose/omit NPA information, how such information is communicated, why clinicians discuss/do not discuss information, and if considerations regarding disease acceptance guides their information provision. Atlas-ti will be used to support inductive and deductive content analysis. Results: We are providing detailed information on the 'what, how, when, and why' of communicating NPA results, from the perspective of clinicians, and discuss similarities and differences among clinicians. Conclusion: Results may provide insight into clinicians' considerations about how they communicate NPA results during diagnostic disclosure, thereby optimizing the path towards disease acceptance. Additionally, we may identify difficulties in communication of NPAs which, if addressed, could improve patients' insight, functioning, and well-being.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-39Design for dementia: assessing the applicability and useability of a new technology to help diagnose dementia

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Background: Identifying signs of dementia at an early stage can be challenging. Current diagnostic tools are costly, invasive, and lack specificity and sensitivity. There is growing evidence showing that eye changes can provide helpful information into the early stages of dementia. However, there are still few technologies able to do this. Cambridge Vision Technology is pioneering a technology able to read the eyes and provide an easy and reliable way to spot early changes in the brain. It is firstly important to ensure the technology is fit for purpose and implemented at the right time. Objectives: We aimed to understand: 1. The challenges faced by people with dementia and caregivers during the dementia diagnostic journey; 2. How individuals perceive the applicability and useability of the technology. Methods: The project involved qualitative methods. For a) we conducted online focus-group with people with dementia and caregivers to discuss experiences of being diagnosed and how the journey could be improved. For b) we conducted in-person interviews with people at early stages of dementia, caregivers, and those over 50 without memory concerns, to get their views on the technology. Interviews were transcribed and analysed using thematic analysis. Ethical approval was obtained from the University of Bradford. Results: Participants reported several challenges during the diagnostic journey. These included an

unclear and lengthy diagnostic pathway, lack of knowledge and awareness about dementia among healthcare professionals, and limited information about dementia-specific support. Participants welcomed the technology highlighting its ease of use and its potential for adoption in the future. Suggestions for its future development were made. Conclusion: This project adds to the evidence into how technology can be co-developed effectively with the end-users. Findings will provide insights for tailoring the technology to ensure its usability and applicability for people living with dementia.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-40The prevalence of neuropsychiatric symptoms during crises in persons with dementia – a systematic review

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Dementia affects millions worldwide, with neuropsychiatric symptoms impacting up to 90% of those affected during the course of the disease. These symptoms often escalate to crises, posing significant challenges for patients, caregivers, and healthcare systems. Delirium is a frequent and treatable cause for neuropsychiatric symptoms in people with dementia. The aim of our review was to determine the prevalence of neuropsychiatric symptoms and delirium in patients with dementia at the time of a crisis. The review was guided by PRISMA guidelines. A search was performed in six bibliographic databases. Data extraction covered neuropsychiatric symptoms, diagnosed delirium, use of delirium screening tools, and discharge location. Risk of bias assessment was performed with the Mixed Method Assessment Tool (MMAT). A meta-analysis or narrative synthesis will be performed depending on heterogeneity. We included 70 studies published between 1977 to 2023. These studies describe general crises (n = 46), and behavioural crises (n = 24). In the former, findings reveal considerable variability in the documented prevalence rates of individual neuropsychiatric symptoms, ranging from 7% for euphoria to 59% for activity disturbance. Additionally, 13 out of 70 studies reported a prevalence of delirium between 0% and 60%. The three studies that utilized a screening tool for delirium showed a higher prevalence than those that did not. Based on the preliminary data, we conclude that neuropsychiatric symptoms occur frequently in persons with dementia at the time of a crisis, and somatic disease underlying delirium may be a frequent under detected cause of

psychiatric symptoms. Our findings will enhance the understanding of crisis phenomenology and support targeted interventions to improve dementia care. This study is part of the Dutch research project entitled SPREAD+ (Sustainable and PeRsonalisEd Advances in Dementia care).

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-41Measuring empathy in people with young-onset dementia: validity of the newly developed Nummenmaa emotion experience test and empathic accuracy task – clinical

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Objectives. An important affected domain in various subtypes of young-onset dementia (YOD) is social cognition (SC), which is the ability to perceive, process and respond appropriately to social information. SC impairments can significantly impact social behaviour and interpersonal relationships. Therefore, it is imperative to accurately assess SC impairments in patients with YOD. Currently, valid and well-normed tests exist only for assessing emotion recognition. Therefore, two new tests were developed for measuring other aspects of SC: bodily emotion experience and empathy. The aim of the current study was to analyse the association of the two new tests with other SC measures (convergent validity) and a purely cognitive test (divergent validity). Methods. 62 healthy participants were included. The Nummenmaa Emotion Experience Test (NEET) measures bodily emotion experience, and the Empathic Accuracy Task - Clinical (EAT-C) measures cognitive and affective empathy. With parametric and non-parametric correlation analyses, associations with the Facial Expressions of Emotion: stimuli and test (FEEST), the Toronto Alexithymia Scale (TAS-20), a ToM battery (including items of the Hinting Task, Faux-Pas, Cartoons and Story-based Empathy Task) and the Trail-Making Test B, were studied. Results. There is no significant association between TMT and NEET (rs=-.149, p=.249) and EAT-C (rs=-.042, p=.749). There is a significant, but small, association between NEET and FEEST (rs=.277, p=.029) Furthermore, EAT-C total is significantly associated with ToM Cartoons (rs = .255, p=.046). The external orientation subscale of the TAS-20 is significantly associated with EAT-C total (r =-.284, p=.025) and EAT-C Affective (r=-.376, p=.003). EAT Cognitive is significantly associated with Hinting Task (rs=.274, p=.031), Faux-Pas

(rs=.263, p=.039) and Story-based empathy task (rs=.265, p=.038). Conclusions. The NEET and EAT-C are not associated with a purely cognitive test, but are associated with (sub)tests of SC measuring similar or related aspects. These preliminary results on construct validity of the new tests seem promising.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-42Neuropsychological tests at the Italian centers for cognitive disorders and dementias

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Background: In the 2022 the Italian National Institute of Health carried out a national survey on CCDDs, with the purpose of updating data on CCDDs' infrastructure and organization. Aims: Neuropsychological assessment (NPA) plays a central role in the clinical evaluation of cognitive impairment and dementia. The principal aim was to investigate the current use of Neuropsychological (NP) tests in Italian CCDDs compared to prevoius surveys. Methods: An online survey was conducted in all Italian CCDDs, the response rate was 84%. The questionnaire collected information on: NP tools adopted, staff composition, geographical macro-areas location and offered services. To verify the use of a comprehensive NPA in the diagnosis of cognitive disorders and dementia, we identified a minimum core test (MCT). Results: The current use of NP tests has shown stability over the past years. The CCDDs using MCT significantly increased from 45.7% in 2015 to the current 57.1%. Territorial CCDDs using MCT significantly increased from 24.9% in 2015 to 37% in 2022 (p = 0.004). As multivariable results, the presence of psychologist/neuropsychologist in the staff and the university-based CCDDs increased the probability of using MCT over than 9 times and

5 times (OR =9.2; p<0.001 and OR=5.4; p =0.002, respectively), while CCDDs in Southern Islands had the probability of 60% lower than those in the North (OR = 0.4; p =0.001). Discussion: The 43% of CCDDs do not declare an MCT and large disparities remain between geographical areas in Italy. The presence of the psychologist/neuropsychologist in the staff has a key role for the adoption of MCT and NPA, which are crucial in the diagnostic process. An intervention by health policymakers is urgently needed to improve diagnostic appropriateness and overcome regional differences. The project was carried out with the technical and financial support of the Ministry of Health chapter-2302.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-43Social and lifestyle factors and their impact on cognition: a survey study in older adults

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Background: The older population is increasing. By 2050, it will be twice what it is now. It is important that healthy cognitive ageing is well understood, as well as pathological disorders of ageing such as Alzheimer's disease and dementia. Research suggests that being widowed can be predictive of dementia, as does not having children. Furthermore, when these factors were combined, the risk of dementia was 1.3 times higher in parents who were widowed, and there was a 2.2 times increased risk of dementia in widows without children (as compared to a group that were married with children). Separate research has looked at 'busyness' and cognition. Results showed that 'busier' people show higher scores on cognitive function tests than less busy people. Aims and Methods: This project will investigate the interactions between busyness and partner loss in older adults. This study involves the University of Bradford, UK, and the University of Bologna, Italy. Each partner will collect data independently and online. Demographic information will be taken, as well as information about the relationship status of the participant, along with details about their children (if any), living arrangements, loneliness, busyness, social activity, and underlying health conditions. Participants will also complete the Cognitive Failures Questionnaire (CFQ) and the Prospective-Retrospective Memory Questionnaire (PRM). Expected results: We hypothesise that partner loss and not having children will result in the lowest scores on the CFQ and PRM. However, we predict a positive association between CFQ and PRM scores, social activity (online and face-to-face) and busyness. Conclusions: If people who

have higher levels of busyness after partner loss show better scores on the CFQ and PRM as compared to those who are less busy, then this has important implications for cognitive ageing, particularly in those who have lost a partner.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-44Prevalence and correlates of neuropsychiatric symptoms in individuals referred to a memory clinic, and the distress experienced by their caregivers

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Background: Neuropsychiatric symptoms (NPS) are common in dementia, even appearing in prodromal stages. However, limited research has explored NPS prevalence at diagnosis in memory clinics. Early NPS assessment may aid in the diagnostic process and predict disease prognosis. The Oxford Brain Health Clinic (BHC), launched in August 2020, offers comprehensive assessments for individuals with suspected memory disturbances before their diagnosis at memory clinics. This study explores NPS prevalence and caregiver distress in BHC patients and examines their associated factors. Method: BHC patients with valid Neuropsychiatric Inventory (NPI) scores and subsequent diagnoses (dementia, MCI, or no memory disorder) were included. Data analysed included patient demographics, lifestyle, frailty, depression, cognition, cognitive decline, and caregiver demographics, distress. Descriptive analyses and comparisons between subgroups with different diagnoses were conducted. Additionally, linear regression analyses were performed to explore factors associated with NPS and caregiver distress. Results: Among 241 patients (mean age 77.5 ± 6.3 years), 53.5% were subsequently diagnosed with dementia, 23.7% with MCI, and 22.8% had no memory disorder. NPS were present in 202 patients (83.8%), with a mean of 2.78 NPS and a mean total NPS severity score of 4.43 (range 0-36). Patients without memory disorder had a higher number and greater severity of NPS compared to those with MCI

despite healthier cognitive status, at NPS levels similar to those with dementia. Additionally, their caregivers experienced higher distress. The total number of NPS moderately correlated with cognitive decline [R(146)=0.50, p<0.001] and caregiver distress[R(146)=0.60, p<0.001], but not cognitive status. Regression analysis indicated cognitive decline and caregiver distress were associated with NPS [R2= 0.401, F(2,145)=50.74, p<0.001]. Conclusion: NPS were highly prevalent in individuals referred to memory clinics. The NPS is associated with cognitive decline, suggesting NPS maybe an early diagnostic or prognostic sign for progression to dementia. Longitudinal research is needed to confirm this hypothesis.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-45Long-term cost-effectiveness of a more precise dementia diagnosis using amyloid-PET: a matched cohort study

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This study evaluates the long-term cost-effectiveness of a more precise diagnosis by adding amyloid-PET to a standard diagnostic workup in a memory clinic setting from a healthcare perspective. In 2014-2016, Amsterdam Dementia Cohort patients were offered an amyloid-PET as part of their diagnostic workup. Those who received an amyloid-PET were propensity-score matched to participants without a PET, creating two balanced groups containing 442 patients each. Statistics Netherlands provided healthcare costs, institutionalization, and mortality data for seven years of follow-up until 2021. The effect outcomes of this study were time to institutionalization (TTI) and time to death (TTD) after diagnosis. Considered costs differed between these outcomes: for the TTI, health insurance costs were considered, whereas costs for the TTD included also costs of institutionalization. Differences in effects and costs were estimated using bivariate regression analysis and combined into the Incremental Cost-Effectiveness Ratios (ICER). Bootstrapping was used to estimate 95% confidence intervals (CI) around the cost and effect differences. Cost-effectiveness acceptability curves were estimated to show the probability that PET is cost-effective compared to no-PET for a willingness to pay (WTP) values up to the threshold of

€290, which equals the costs of one day living in the institution. For both outcomes, the point estimate of ICER suggests that the intervention is dominant. On average, patients in the PET-group were institutionalized 173 days (CI: 97–252) later while their costs were €1,196 (CI: -7,502 to 4,576) lower. When TTD outcome was considered, patients in the PET group lived 112 days (CI: 51–171) longer and their costs were €13,385 (CI: -28,748 to 1,656) lower. The probability of the intervention being cost-effective exceeds 99% for both outcomes already at the WTP threshold €50. The results suggest that a more precise diagnosis by the means of amyloid-PET is a cost-effective strategy.

Patient pathways - Detection and diagnosis

POS1. Posters - Patient pathways

POS1-47Saccadic eye movement tasks in AD and MCI: comparing predictability power and discriminatory ability with executive function tasks

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Executive function (EF) impairments are common in AD and MCI. While EF domains are predominantly assessed through traditional paper-pencil and computerized tasks, there is a growing body of research exploring the usage of eye movement (EM) tasks, specifically saccadic EM, in detecting cognitive decline earlier and their potential for differentiating different types of MCI. In addition, EM tasks are less influenced by factors such as motor skills, language abilities, and literacy levels Which enhances their potential as promising tools in clinical settings. However, there is a lack of studies on the association between different EM tasks under different conditions (step, gap and overlap) and various EF tasks. Also, it is remained unclear whether EM paradigms are superior predictors of AD and MCI compared to EF tasks, and which one is more effective at distinguishing between healthy individuals and patients. To comprehend the knowledge, we initiated a multilevel plan. Initially, we conducted a systematic review. 26 eligible studies were included in the final report and 57 tasks were examined. Our findings revealed deficits in EF, particularly in cognitive flexibility and inhibitory control among individuals with AD and MCI. The TMT-B and category fluency (animal) were highlighted as highly discriminative, while the Stroop task, DST, and VFT (letter) also showed effectiveness, albeit with slightly less robustness. Subsequently, we extended on a comprehensive exploratory search to examine the relationship between four specific EM tasks—interleaved prosaccade, go-no-go, and go right

and no-go left—with EF tasks (in progress - Data collection ongoing) in 67 healthy younger adults. The most correlated tasks will be administrated on older adults and individuals with MCI and AD. We'll evaluate these tasks' predictive abilities for disease and compare their capacity to differentiate patients from healthy individuals using AUC and ROC analysis.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-48Improving the mental health practitioners' confidence around diabetes management in patients with serious mental illness including dementia, using QMIS methodology

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In the United Kingdom, diabetes is five times commoner in people with serious mental illness (SMI) including dementia, with most patients unaware of their diabetes and likely to die 20 years earlier compared with those without SMI. Often, the mental health practitioner (MHP) is their only contact with the national health service (NHS). Diabetes costs the NHS around £10 billion a year, 10% of its budget, with 80% spent on treating complications. Early diagnosis and referral using appropriate pathways along with improving the MHP's confidence has shown to prevent diabetes related complications. However, MHP's often have little time to address physical health issues although vital in a holistic care plan. In Newbury Older Peoples Community Mental Health Service we adopted QMIS - Quality Improvement Management System, a set of lean management and improvement tools to help staff collaboratively maximise value adding activities, hence quality improvement, whilst reducing inefficient processes. QMIS involves identifying the problem, setting SMART goals, a Root Cause Analysis, countermeasures, outcomes and plans for continuous service improvement. We identified the need to improve knowledge base in diabetes from a pre-training questionnaire with 10 participating MHP's. Bite-sized training based on the resources provided from the Cambridge Diabetes Education Programme (CDEP), Diabetes UK, RCPsych and the NHS 5 Year Forward Plan, was delivered which was role relevant, concise, and addressed diet, hypoglycaemia, hyperglycaemia, complications and knowledge of service pathways addressing onward referrals to other relevant services - for example, community diabetes nurse team, eye check or foot care. Post-training questionnaires showed

significant improvement in MHP confidence evident from positive feedback from MHP's and patients. The bite size training was incorporated into the team resource folder for incoming MHP's as well providing a refresher, hence part of a continuing service improvement initiative to ensure parity of esteem.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-50Supportive care needs of those with comorbid cancer and dementia and their caregivers: a systematic review

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Introduction: People are living longer, so an increase in the prevalence of comorbid cancer-dementia is expected. Despite a dearth of literature in this area, research has noted that individuals diagnosed with both cancer and dementia (cancer-dementia) face complex healthcare challenges and often achieve poorer clinical outcomes compared to individuals with cancer alone. There is a significant gap in knowledge surrounding the supportive care needs of those with cancer-dementia and their caregivers, and best care practices for those with cancer-dementia and their caregivers. To the authors knowledge, this study will represent the first systematic review to identify and examine the supportive care needs of those with cancer-dementia and their caregivers. Thus, signifying an important step for cancer-dementia research. Aims: 1. To identify the supportive care needs of cancer-dementia survivors and their caregivers. 2. To explore whether these care needs are being met or unmet within healthcare systems internationally. 3. To identify the factors related to unmet care needs (barriers and facilitators to meeting care needs) within healthcare systems internationally. Method: Systematic searches were performed using relevant databases; CINAHL, Medline, PsychINFO, Embase and Web of Science, and included a mixture of controlled vocabulary and free text terms. Data synthesis employed a thematic synthesis method (Thomas & Harden, 2008). Results: Database searches resulted in 11 qualitative articles being identified. Although data synthesis has not yet been completed, data will be analysed using three stages of thematic synthesis: 1. Line by line coding, 2. Organising 'free codes' into descriptive themes, and 3. Developing analytical themes. Although this study is ongoing and supportive care needs have yet to be identified, considering the dearth of research surrounding cancer-dementia, I believe a poster or presentation detailing this

research so far and the implications of cancer-dementia would be a worthwhile contribution to your conference.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-51How to prevent and manage crisis situations in persons living with dementia at home: a systematic review

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Background: Crisis situations are common for people living with dementia at home, often caused by falls, challenging behaviour, or caregiver burnout. Crises frequently lead to acute hospital and nursing home admissions. To prevent and manage crises appropriately, we aim to understand the process leading up to and throughout crises from the perspectives of persons living with dementia, informal carers, and healthcare professionals. Additionally, we want to identify existing interventions aimed at crisis prevention and management. Methods: Medline/PubMed, EMBASE, Cochrane, CINAHL, and PsycINFO were searched for relevant articles published since 2000. We included (randomised) trials and qualitative studies. Title/abstract screening was performed in duplo using the artificial intelligence tool ASreview. Due to discrepancies in reviewer inclusion, abstracts of all included articles were independently rescreened by two researchers, before full-text screening. Methodological quality is assessed with the Mixed Method Appraisal Tool. Results sections and intervention descriptions are thematically synthesized. Preliminary results: The initial search yielded 17406 citations. 935 abstracts were included by one or both screeners using ASreview, of which 106 remained after rescreening. Full-text screening resulted in inclusion of 20 qualitative and 35 intervention studies. Preliminary results from the qualitative studies indicate that crises arise from a complicated process of trying to stay at home amid risks and navigating professional and informal care systems. Intervention studies can be categorized in

care coordination, monitoring and caregiver support interventions, but effect sizes and evidence is limited. Discussion: This study explores the process of crisis situations of people living with dementia from the perspective of various stakeholders. Additional extensive analysis of the qualitative studies will help to further unravel the process leading up to and throughout crisis. The results will guide the development of targeted interventions utilizing early signals of change to prevent future crises.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-52Involuntary care within the care and compulsion act in people with dementia residing in nursing homes in the Netherlands

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Background: Involuntary care often occurs in people with dementia and can has substantial impact on their quality of life. In The Netherlands, the Care and Compulsion Act (CCA) was launched in 2020 to arrange the rights of people with a psychogeriatric disorder like dementia who receive involuntary care. The CCA describes under which conditions involuntary care can be provided and how this care should be evaluated. This study aims to describe the types of involuntary care that people with dementia received within the CCA and to examine to what extent the involuntary care was evaluated timely. Methods: Pseudonymized information of people with dementia who resided at psychogeriatric wards and received involuntary care under the CCA during 2021 or 2022 was extracted from the electronic medical record (EHR) Ysis. This EHR is used by approximately half of the nursing homes in the Netherlands. Descriptive statistics were used to examine the frequency and types of involuntary care measures and the extent to which the measures were evaluated within the recommended timeframes. Results: 5087 involuntary care measures were applied in 2863 people with dementia. 63% received one measure during the study period, 20% received two measures and 17% received three or more measures. The “restriction of freedom to move (fixation)” was the most frequently used measure (2504 times), followed by “administration of nutrition, moisture or medication, medical procedures or therapeutic measures” (2080 times) and “separation” (155 times). Measures were evaluated timely in

68% of the cases. Conclusion: This is the first study to provide insight in the types and frequency of involuntary care measures that are applied under the CCA in people with dementia on a large scale. Fixation is the most frequently used type of involuntary care. There is room for improvement regarding timely evaluation of applied involuntary care measures.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-53Safety of plasma exchange with albumin replacement in Alzheimer's disease: a prospective cohort study in a single center

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Background: Research indicates dynamic balance of β-amyloid peptide (Aβ) between cerebrospinal fluid (CSF) and plasma compartments. Therapeutic plasma exchange (TPE) may influence in this balance, reducing amyloid levels in CNS, potentially benefiting Alzheimer's disease (AD) patients, as seen in AMBAR study. This study aims to assess the safety of TPE with albumin replacement in mild to moderate syndromic AD in real-world settings.
Methods: This observational study included all consecutive patients with AD treated in our center from June 2021 to February 2024. Patient eligibility was determined through initial visits where inclusion and exclusion criteria were confirmed. Multidisciplinary clinical assessments were conducted as baseline evaluations and comprehensive laboratory. Apheresis procedures were performed using the Optia (Terumo®) continuous flow centrifugation cell separator, ensuring continuous plasma exchange. Treatment consisted in six biweekly TPE with albumin replacement (Albutein Grifols®) intensive periods, followed by 12 monthly TPE maintenance. Continuous monitoring and direct supervision by specialists ensured procedural safety. Regular clinical interviews were conducted, with family involvement and post-treatment follow-ups for adverse effects assessment.

Results: 122 patients met inclusion criteria and initiated TPE treatment. Ninety-seven persons (79.5%) completed 6 TPE, 68 (55.7%) completed 12 TPE, 45 (36.8%) completed 18 TPE and underwent evaluation. Seventy-five participants were women (61%) with a mean age of 72.4±6.7. Mean MMSE score was 20.1±4.7, participants had an average of 11 years of education. Safety Endpoints: Out of 2,129 TPE procedures performed, 97.6% were uneventful, with only 2.3% experiencing mild adverse events, including hypotension (1.3%), discomfort (0.1%), syncope (0.3%), paraesthesia (0.0%), and other minor issues (0.3%). Flebitis and serious adverse events were not reported.
Conclusion: These findings suggest that TPE with albumin replacement is safe in mild to moderate syndromic AD patients. Further research with larger populations is warranted to elucidate the role of TPE in the evolving landscape of AD treatments.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-54Efficacy of plasma exchange with albumin replacement in Alzheimer's disease: a prospective cohort study in a single center

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Background: Research suggests a dynamic balance of amyloid-β (Aβ) peptide between cerebrospinal fluid (CSF) and plasma compartments. Therapeutic plasma exchange (TPE) reduces peripheral Aβ, potentially altering this balance and lowering CNS amyloid levels. TPE has shown efficacy in alleviating symptoms and slowing Alzheimer's disease. This study aims to validate prior findings on the cognitive benefits of TPE with albumin replacement in mild to moderate syndromic Alzheimer's Disease (AD) within real-world conditions.
Methods: This observational study included all consecutive patients with AD treated in our center from June 2021 to February 2024. Treatment consisted in six biweekly TPE intensive

periods, followed by at least 12 monthly TPE. Apheresis procedures were performed using Optia (Terumo®) continuous flow centrifugation cell separator with albumin replacement (Albutein Grifols®). Neurological, neuropsychological, and functional perception assessments were conducted at baseline, three months, nine months, and fifteen months for all patients.
Results: 122 patients met the inclusion criteria and initiated TPE treatment. By the study's end, 97 (79.5%) completed 6 TPE, 68 (55.7%) completed 12 TPE, and 45 (36.8%) completed 18 TPE and underwent evaluation. Seventy-five participants were women (61%) with a mean age of 72.4±6.7. The mean MMSE score was 20.1±4.7, and participants had an average of 11 years of education.
Cognitive Outcomes: While primary endpoints such as MMSE, Clock test, and BNT test showed a statistically significant mild decrement ($p < 0.05$), cognitive composite (NBACE) indicated stability and improvement during treatment. Patient-related outcomes (PROs) showed stabilization or improvement in 84.4% of patients based on the IGI scale, with similar perceptions reported by caregivers (77.97%).
Conclusion: Findings suggest that TPE with albumin replacement is efficient in mild to moderate syndromic AD patients and may offer cognitive stabilization benefits. Further research with larger populations is warranted to elucidate the role of TPE in the evolving landscape of AD treatments.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-55What do professionals think of specific recommendations for VCI care? results of a modified delphi study with health care professionals

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Background: Vascular cognitive impairment (VCI) is an umbrella-term covering all cognitive impairment from mild cognitive impairment to dementia due to vascular etiologies. Previous studies mapped needs and perspectives of people with VCI, informal caregivers and healthcare professionals on (post-diagnostic) care and support. We aim to translate these insights into recommendations for clinical care. Methods: We conducted a

modified DELPHI-procedure with an expert group (N=34) of healthcare professionals and researchers in the dementia and stroke care field. Based on Dutch Care standards for dementia and stroke care and previous studies, 27 statements were formulated by the research team. In three rounds, participants were asked on a 4-point Likert scale how much they agreed with statements as 'suitable as a specific recommendation for people with cognitive decline due to vascular causes'. Participants were encouraged to elaborate on their answer in open fields. After each round, level of agreement was calculated and evaluated whether consensus was reached. Qualitative data guided potential modifications to the statements. Results: Of the formulated statements, four were accepted in round 1, ten were accepted in round 2, and nine in round 3. Ultimately, 23 statements reached consensus, twenty very high (88-100% Likert score 3 or 4, 79-96% score 4) and three high (82-96% score 3 or 4, 73-75% score 4). Accepted statements include recommendations on recognition and management of symptoms common in people with VCI (i.e. apathy and fluctuations), awareness of care opportunities in and collaboration between various care pathways and the importance of timely assigning overall coordinating professional. Discussion: Experts agreed on most specific recommendations for VCI care across the disease trajectory. Although some recommendations may rather reflect an 'ideological' situation, the expert-agreed statements can provide guidance in striving towards optimal care for people with VCI.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-56Agitation in Alzheimer's dementia: conceptual framework to demonstrate the burden of illness

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Introduction: Agitation in Alzheimer's dementia (AAD) confers significant humanistic and economic burden; however, factors driving this burden are poorly understood. The objective of this study was to review evidence on the burden of AAD and develop a conceptual framework capturing its effects on patients, their families, care teams, and society, which

can then be used to guide further research into reducing the burden of AAD.
Methods: A targeted literature review on the burden of AAD was conducted. Data were classified into societal, patient/family/care team, and mitigating factors. A conceptual framework (i.e., a visual representation of variables and associations between them) was developed to map the relationships between factors and illustrate the precedents and downstream effects of agitated behaviors on patient and caregiver outcomes, including healthcare resource utilization (HCRU), costs, and admission to long term care (LTC).
Results: Agitated behaviors were found to directly impact caregiving demands in terms of the number of hours required to care for patients. Levels of caregiver stress were found to be associated with the frequency and intensity of AAD. Burden also extended to care teams via increased HCRU (i.e., pharmacy, outpatient, inpatient, and emergency room visits), and consequently costs, relative to non-agitated patients. Indirectly, through caregiving demands, agitation affected the rate of placement in formal care and LTC, both of which are associated with incremental costs. Evidence also indicated that mitigating factors such as pharmacological treatment could impact the frequency and intensity of agitated behaviors.
Conclusions: This study demonstrated the complex interplay of factors which drive the burden of AAD and the need for novel ways to improve outcomes for those impacted by the disease. Better insight into the mechanism by which agitated behaviors influence caregiver demands and stress could help improve mitigation strategies both within family units and the larger health system.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-57A survey testing the compliance with national guidance of the integrated care pathways on dementia in Italy

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Introduction: The implementation of integrated care pathways (ICPs) could represent a key element in terms of the quality of care and management of people with dementia. This study aimed to collect the ICPs for dementia available in Italy and assess their compliance with the national guidance for ICPs for dementia. The project was carried out with the technical and financial support of the Ministry of Health (Chapter 2302). Method: ICPs were identified through different channels: i) the survey of the Italian Centers for Cognitive Disorders and Dementia by the NIH; ii) institutional websites of the Regions and Local Health Authorities (LHAs); iii) direct communication with general directorates of the LHAs and other experts. A checklist developed according to national guidance and based on three domains (Reference Context, Pathway Elements and Integrated Management, Local Pathway Construction) and 43 items (score 0-1) was applied. Two researchers conducted a blind evaluation, and a third researcher resolved the conflicts. Results: A total of 39 ICPs met the inclusion criteria and were considered for the compliance check (11 regional, 28 local). The mean total score was 23.4 ± 7.8 for the ICPs of the Regions and 22.7 ± 5.7 for those of the LHAs, ranging from 10/43 (Umbria) to 33/43 (Lombardy) for regional ICPs and from 11/43 (Marca Trevigiana, EOD) to 31/43 (Naples2) for local ICPs. The concordance between raters was excellent for regional ICPs and good for local ICPs, with no significant differences between the mean scores assigned to the ICPs, both overall and in the individual domains. Conclusion: The analysis revealed a relevant heterogeneity in ICPs' compliance with the national guidance. It highlighted several concerns about monitoring ICPs, as well as equity, considering the number of people with dementia and relatives who can benefit from an ICP for dementia diagnosis, care, and assistance.

Patient pathways - Treatment and medical management

POS1. Posters - Patient pathways

POS1-58Developing resources for prescribers of psychotropic medication for non-cognitive symptoms of dementia

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National Clinical Guideline No. 21 ("Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia"), was published in 2019 in Ireland in order to fulfil a priority of the National Dementia Strategy to develop guidance material on appropriate management of medication for people with dementia, in particular psychotropic medication. An implementation programme commenced in 2022 on a phased basis across relevant care settings. A key output to date has been the development of resources for staff involved in the prescribing of psychotropic medications for non-cognitive symptoms of dementia. This includes an information leaflet, a document to support comprehensive assessment, and a 1-hour education session. The information leaflet outlines the recommendations and good practice points of National Clinical Guideline No. 21, provides information on comprehensive assessment, and signposts to further supports. One of the key recommendations of National Clinical Guideline No. 21 relates to the conduct of a comprehensive assessment prior to considering any psychotropic medication in a person with dementia. A document to support comprehensive assessment as well as a video recording on this topic were developed in support of this recommendation. In addition, an education session targeted at prescribers of psychotropic medication was developed and is currently undergoing national roll-out across a range of settings. The aim of these resources is to provide readily accessible, concise information on the appropriate prescribing of psychotropic medications for non-cognitive symptoms of dementia. These are part of a range of education resources developed, which also includes eLearning and Facilitator Education. An evaluation of the implementation programme is being conducted to establish the reach and impact of the education resources. It is hoped that the education programme will increase awareness of the guideline as well as embedding the guideline across settings and improving the management of dementia.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-59Communication training for medical professionals: proof of concept

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Despite the prevalence of patients living with dementia, physicians and medical students in particular, have received little or no dementia-specific training to help them communicate effectively with this population. Connecting and communicating with persons living

cognitive change requires specific skills. These skills are taught in the Validation for Physicians and Medical Provider training, based upon the evidence-based Validation method by Naomi Feil.
Developed with physicians and pedagogical expert in online learning, the training was designed for healthcare professionals, specifically doctors, with quality of care for patients and their carers in mind. The training comprised of a variety of teaching methods including: online on-demand videos, quizzes, case studies, and live webinars for each of the five blocks.
The pilot program included physicians and other healthcare professionals. Pre and Post surveys consisted of a knowledge scale and SRDB (self-efficacy) ranked on a Likert scale of 1 to 5 and analyzed using SPSS. Post-training individual interviews concluded the beta-testing. Thirty professionals enrolled in the training; eight participants completed every aspect of the beta-testing. Despite the small sample size, there were trends approaching significance in knowledge and self-efficacy. Participants highly valued the contents of the training as well as the pedagogy.
Technical problems were the main reason for attrition. Overall, the Validation method was found useful in practice, improved confidence, knowledge, and communication behaviors. Improvements are needed in the choices for validated measures and the online platform.
“Validation has made me a better doctor. It has changed my perspective on aging” (participant).

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-60Transforming care: exploring psychosocial support methods (PSM) in Dutch nursing homes

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Ensuring and maintaining quality of life for vulnerable elderly individuals lies at the core of nursing home care. Beyond medical attention, prioritizing person-centered care tailored to residents' needs and wishes is essential. This necessitates a paradigm shift from a medical-centric model to one embracing the psychosocial framework, wherein psychosocial support becomes integral to daily care.
To facilitate this transition, the implementation of Psychosocial support methods (PSM)

emerges as a pivotal strategy. PSMs provide a cohesive approach and practical tools to act more systematically, ultimately enhancing their ability to address residents' needs and preferences. Consequently, the quality of life improves, while concurrently fostering professional growth and competence among healthcare providers.
This presentation aims to disseminate the latest findings from ongoing extensive research in the field. It aims to address common practical inquiries: What constitutes a PSM (including criteria)? Which interventions are currently accessible in the Netherlands, and for which resident subgroups? Moreover, how do we evaluate the efficacy of these interventions for both residents and staff?
By shedding light on these aspects, this research endeavours to empower nursing homes in making informed decisions regarding PSM, thereby advancing the quality of care provided to residents.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-61Coping styles of informal caregivers of persons with dementia in Singapore

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Background: Informal caregivers of persons with dementia (PWD) may use different coping styles when faced with caregiving challenges. This study aims to investigate how caregivers respond to these challenges.
Methods: A cross-sectional survey of 281 primary caregivers of PWD in Singapore was conducted. Path analysis was used to examine the relationship between caregiving stressors (functional dependence, memory and behavioural problems, and weekly caregiving hours), knowledge of dementia, caregiving burden and coping styles.
Results: Weekly caregiving hours were significantly positively correlated with caregivers' emotion-focused and avoidant coping styles. Path analysis results suggested a full mediating role of caregiver burden between memory & behavioural problems and caregivers' primary coping style, between weekly caregiving hours and problem-focused and avoidant coping styles and a partial mediating role of caregiver burden between weekly caregiving tasks and emotion-focused coping style (CFI=0.966, TLI=0.920, RMSEA=0.061). Informal caregivers with better knowledge about dementia were more likely to use a problem-focused coping style, while those who spent more time caring for PWD were more likely to use an emotion-

focused coping style. Caregivers with higher burden were more likely to use more avoidant coping style compared to emotion-focused and problem-focused coping styles.
Discussion: This study allowed us to better understand the relationship between caregiving stressors and caregiver coping styles. It also highlighted the finding that dementia caregivers in Singapore seem to have preference for avoidant coping style and this coping style is usually considered maladaptive. Understanding coping styles enables us to better able to focus resources where it is needed in order to reduce caregiver burnout and thus enhance their quality of life and delay institutionalisation of PWD.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-62Involving key stakeholders in development of a low-intensity behavioral activation intervention for people with dementia: a qualitative study

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Background: People with dementia commonly experience depression, and are in need of psychological support. Despite this unmet need, access to psychological support remains inadequate. To address the support gap, a low-intensity behavioral activation intervention was developed for people with dementia and depression in the United Kingdom. Before using the intervention in Sweden, adaptation to the Swedish healthcare and cultural context is required. The aim of this study was to explore needs and preferences of key stakeholders (people with dementia, informal caregivers, healthcare and social care professionals, and non-profit organizations) to enhance intervention relevancy, cultural appropriateness, and acceptability for people with dementia in Sweden.
Method: Semi-structured interviews (n=40) and three separate focus groups (n=12) were conducted with key stakeholders (n=52). Written intervention workbook drafts and the proposed intervention delivery model description were provided prior to interviews. A topic guide explored needs and preferences regarding intervention content, language, case stories, and delivery model (including setting, support type, and guidance provided). Transcribed interviews were analyzed using qualitative content analysis.
Results: Three themes were identified: Content, Delivery procedures, and Illness trajectory. The theme Content highlighted the need for cultural adaptation to the Swedish context and

improve inclusivity by better representing people with dementia in different life situations. The theme Delivery procedures identified a need for additional and flexible caregiver support. The theme Illness trajectory highlighted a need to receive the intervention early in the dementia trajectory to facilitate intervention engagement. Results informed adaptations including the development of modern illustrations and additional case stories with improved relevancy to Swedish culture and the provision of additional caregiver support sessions. Conclusion: Involving key stakeholders is central to intervention development and to enhance the relevancy, cultural appropriateness, acceptability of complex interventions. Results will inform a future pragmatic feasibility study to further explore feasibility and acceptability of the intervention.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-63Triadic communication during dementia care: a conversation analytic study

Hannah Wheat, Hannah Wheat
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Healthcare professionals' interactions with people with dementia often involve a companion. Studies suggest that the companion's presence may impact the involvement of the person with dementia and shape discussion content. Existing studies have focused on healthcare interactions where the person with dementia is the sole recipient of care. However, in certain healthcare settings, support is extended to both the person with dementia and their informal carer, creating a unique triadic healthcare dynamic that warrants exploration.
The Dementia PersonAlised Care Team (D-PACT) model provides ongoing support for both informal carers and people with dementia, delivered by a dementia support worker embedded within primary care. In the model's evaluation, the support worker recorded a subset of support meetings, resulting in a dataset of 42 triadic interactions. Conversation analysis (CA) will be applied to this dataset (recordings and detailed transcripts) to understand how practitioners, individuals with dementia, and carers navigate triadic interactions and the dyadic design of the intervention. CA involves exploring how communication achieves social actions in real life - focusing not only what was said, (and visually expressed) but also how the delivery and location of talk (and non verbal communication) can influence the trajectory of an interaction and its outcomes.
This presentation will share findings from the CA analyses, exploring how all participants

managed activities such as setting a split co-agenda, speakership selection, and facework challenges when sensitive topics were raised. Insights into effective communication strategies for dementia support workers (DSWs) and other professionals providing dual support to carers and people with dementia will be provided.
Insights into effective communication strategies for dementia support workers (DSWs) and other professionals providing dual support to carers and people with dementia will be provided. Consideration will be given to whether triadic interactions may lead to different types of outcomes in this support setting.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-64How does active music-making in a group using improvisation affect residents with dementia in care institutions in terms of connectedness and well-being?

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Background: "Music Circles" is an eight-week programme implementing an interactive and creative music-making together with people with dementia, carers, professional musicians and other care home staff. In practice, joint musical improvisation has proven to be a promising method for picking up people with dementia, giving them a sense of security and conveying the feeling of being understood.
Research question: How does active music-making in a group using improvisation affect residents with dementia in care institutions in terms of connectedness (relationship, connectedness & social behaviour) and Here & Now (well-being)?
Method: Multimodal data collection: sociodemographic data, MMSE, qualitative content analysis of ward entries, behavioural observations of people with dementia during the music sessions (video recordings, quantitative evaluations), as well as proxy questionnaires on the subjective well-being of people with dementia before and after the sessions. The Music in Dementia Assessment Scale (MiDAS) was used to observe and analyse the interest, perception of the environment, initiative, involvement and enjoyment of a total of 24 residents in three sessions each (N=72 observations).
Sample: Sample of participants from three "Music Circles" cycles: n=24, average age=86.6 years (range: 75-98), 79.2% women, 20.8% men). MMSE: 9.3 (SD 7.2).

Results: Significant positive difference in all 5 areas before/after music intervention: responsiveness: ($t = -7.646$, $p < .001$); participation/involvement ($t = -9.739$, $p < .001$); interest ($t = -10.854$, $p < .001$); self-initiated behaviour ($t = -7.748$, $p < .001$); enjoyment: ($t = -7.082$, $p < .001$). Interest in music & previous playing of a musical instrument had no influence on the measured effects.
Discussion: Some people with dementia were sometimes agitated and motorically restless during "Music Circles". it was not always clear whether the residents actually played the instruments intentionally, or whether their restlessness was merely transferred to the instrument.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-65How do family carers assist people with dementia? A qualitative observation study of daily tasks

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University of East Anglia

Introduction: As people with dementia progressively experience more difficulties when performing daily tasks, family carers become the main providers of support. The approaches to assistance carers provide have not been investigated in the past and could inform non-pharmacological interventions that focus on carer skills, participation and reduce dependence in daily tasks. The aim was to explore how family carers support people with dementia during the performance of daily tasks.
Methods: A secondary analysis was conducted on observations video-recorded for the TASKed project, where people with dementia completed a task with carer support. Data were analysed using an inductive reflexive thematic analysis approach, based on Braun & Clarke's model. A systematic analysis was conducted increasing credibility and trustworthiness of the findings.
Findings: Video-recordings of twenty-one dyads were included in this study. Five themes were generated depicting how carers supported people with dementia during task performance: 1) Person-enabled assistance, 2) Goal-directed assistance, 3) Carer-led assistance, 4) Partnership-oriented assistance and 5) Bystander.
Conclusion: Our findings suggest carers employ different approaches when assisting people with dementia with daily tasks depending on the ability of the person living with dementia.

Knowledge of these different modes of assistance could help clinicians and researchers understand what works well and what could be changed to facilitate the participation of people with dementia in daily activities. This could also contribute to carer's increased knowledge and skills when supporting their family members in day-to-day tasks.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-66Overview of psychosocial interventions in French dementia facilities

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Fondation Médéric Alzheimer

Introduction: The Fondation Médéric Alzheimer conducts every two years a national survey among French facilities for people with dementia and family carers. These surveys aim to monitor the implementation of the successive national Alzheimer's plans. For the first time, the 2023 survey focuses on psychosocial interventions to find out where and how they are implemented in France.
Methods: This psychosocial interventions survey covered 13,639 facilities identified as being active (10,337 residential settings, 1,542 day care centers, 1,187 information services and 573 family carer support services). The survey was mailed online or in paper in two waves (December 2022 and February 2023) with 3 reminders (May, July and September 2023). Facilities were asked to specify whether they provide psychosocial interventions from a sample list: activities with animals, activities with plants, dance-based activities, memory-based activities, physical activities, musical activities, artistic activities, sensory stimulation, cognitive rehabilitation, cognitive stimulation, or other.
For each intervention provided, facilities were asked to specify whether its objective was therapeutic, its frequency per week, the duration of a session, the facilitator profile (staff member, external facilitator or volunteer), whether the facilitator had undergone specific training, and any reasons for not including participants (advanced dementia stage, behavioural disorders, physical or sensory constraints, personal reasons).
Results: 37% of facilities (4,996) responded to the survey, with a response rate of 36% for residential settings (3,686), 49% for day care centres (760), 33% for information services (388) and 28% for family carer support services (162). The results, which are currently being processed and analysed, will be presented by facilities, psychosocial interventions and geographical areas.

Conclusion: This survey will provide information on the provision of care and support in terms of psychosocial interventions in dementia facilities and any regional disparities.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-67The formal caregivers' sense of competence in management of behavioral symptoms of people with dementia in a nursing home, with tailored activity program for hospitalized

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Introduction: The treatment and management of behavioral and psychological symptoms of dementia require psycho-social approaches, oriented to well-being and to the improvement of the quality of life of the person and caregivers.
The Tailored Activity Program (TAP) is an evidence-based and Occupation-based program of Occupational Therapy, useful for managing BPSD. It includes prescription of significant activities for the person, based on retained skills and interests, defining strategies and training caregivers. It's applicable at home. The Tailored Activity Program for Hospitalized (TAP-H) is the version for hospitals and other services such as Nursing Home. This study's aim is to highlight the variation in the self-perceived sense of competence (SC) of social and health care workers (formal caregiver) involved in the TAP-H. The secondary objective is to highlight the workers' level of readiness.
Methods: We enrolled 28 workers of the Opera Pia Castiglioni Institution (Modena, Italy): 11 involved in TAP-H (group A) and 17 in standard program (group B). We paired them with one or more residents with dementia and behavioral symptoms (17 pairs for each group). We asked workers to self-evaluate their SC in proposing 3 activities, at time t0 and t1 (after two months), with a VAS competence. The OT defined activities and observed workers during that to define the stage of readiness: 1=precontemplation, 2=contemplation, 3=preparation, 4=action/maintenance.
Results: The TAP-H's workers SC increased by approximately 1 point for all activities. Most of them reached the action stage. The standard program's workers' SC and readiness remain almost unchanged.
Conclusions: The TAP is applicable to reduce the behavioral symptoms of people with

dementia and increase the caregivers' SC and readiness, in the Italian context. We hope that the number of certified occupational therapists will continue to increase.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-68Exploring the experiences of psychotherapeutic interventions for people living with dementia and their families

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Background: The need to provide accessible post-diagnostic services and support for people with dementia and their families/caregivers has been widely recognised. Psychotherapeutic interventions, which involve regular dialogue between an individual and a counsellor/therapist, can impact how individuals respond to their diagnosis of dementia and live with the condition. Currently, there is little evidence for the effectiveness of psychotherapeutic interventions, and we do not know what the experiences of people with dementia are.
Objectives: We aimed to explore the experiences of receiving psychotherapeutic interventions for dementia-related issues, and identify barriers and facilitators to access.
Methods: Participants were recruited through NHS Trusts and support groups across England. Semi-structured interviews were conducted with people living with dementia and their family members (n=30), and qualified therapists (n=20).
Results: Using Framework Analysis, four main themes were identified. Aligning expectations, agreeing outcomes, and tailoring therapy helped people to navigate therapy with dementia. Therapist knowledge of dementia and creation of a meaningful therapeutic relationship supported engagement from people with dementia, and helped manage expectations. Therapists focused on creating a sense of safety and managing endings of therapy, acknowledging this could be complex for people with dementia. The role(s) of family members included engagement within the therapeutic process, improving family

communication, with the therapist sometimes seen as relieving family burden. Finally, barriers and facilitators to accessing therapy were highlighted, including readiness for therapy, availability of services, and a clear referral pathway. The impact of dementia on therapy
Future work: Through a series of workshops held in April-June 2024, a set of core competencies are being developed for therapists to deliver therapy to people with dementia.
Conclusions: At a time where no cure is available for dementia, psychotherapeutic interventions can offer important, meaningful, and ongoing support for those living with, and supporting those with, the condition.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-70What do Spanish people living with dementia and their relatives think of the UK-codesigned ICanDo service for supporting activity participation?

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Background: The ICanDo pathway was co-designed in Manchester (IDoService, EU H2020, n° 895620, 2020-2022) to support community dwelling people living with mild to moderate dementia to adopt a more positive outlook on participation in meaningful activities. It is designed to guide individuals to think about the activities they would enjoy and that make sense to them values, which opportunities are available to them and how they could take part in them. It is supported by a workbook providing content and guidance about the three distinct stages (Niedderer et al., 2023). While this tool is still under refinement (ICanDo Service, 2023-2024), the Span-ICanDo study aimed to investigate if the pathway might be perceived as relevant to the Spanish population (Vitalise, Horizon Europe, n° 101007990).
Method:Three one-hour workshops have been organised were respectively conducted with seven people with mild cognitive impairments, two people with mild dementia, and four relatives of individuals with cognitive impairments (INTRAS neuropsychology clinic

services, Valladolid).
Results: Participants perceived the ICanDo pathway as a good tool for encouraging self-reflection and empowerment in people with mild cognitive impairment. They judged it as visually appealing (warm colors, many pictures, font size). They suggested making it even more interactive (i.e., possibility to stick personal pictures or notes). Participants with cognitive impairments highlighted their preference for group sessions as they felt that exploring the workbook and sharing experiences in a group setting could enhance its effectiveness and enjoyment.
Conclusion: Preliminary findings suggest this UK co-designed tool may also be effectively applied in the Spanish context. Participants praised characteristics that guided the initial co-design of the tool (empowerment, making it social, visually attractive) while making new suggestions. A next step would be to set up a pilot to delve further into investigating the transcultural relevance for deploying the ICanDo Pathway in Spain.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-71Music Makes us! The impact of singing and dancing interventions on people living with dementia

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Pharmacological interventions can aid in the management of cognitive symptoms for people with dementia. However, the benefits are often short-lived, accompanied by negative side-effects and are limited for behavioural symptoms such as anxiety, agitation and depressive symptoms. As a result, there is a need for effective non-pharmacological interventions. Psychosocial interventions such as music-based interventions have been shown to enhance mood, relieve stress and improve quality of life for people living with dementia. Singing and dancing interventions in particular have demonstrated value within the field of non-pharmacological and psychosocial interventions. The "Music Makes Us!" singing and dancing interventions were designed by The Brain Charity in collaboration with speech and language therapists and physiotherapists for people living with dementia in residential and community-based settings. This study employed a mixed-methods approach to examine the impact and acceptability of provided singing and dancing interventions. Outcome measures included cognition, quality of life, mood, neuropsychiatric symptoms, social isolation and

loneliness, assessed quantitatively using standardised questionnaires with N=36 people living with dementia. Semi-structured interviews were conducted with N=19 people with dementia, unpaid carers, session facilitators (paid carers and activity coordinators) and session leaders to further examine the impact of music-based intervention services with a specific focus on acceptability, barriers to access, prolonged engagement and potential for remote delivery. Quantitative preliminary results indicate significant improvements in cognitive functioning and quality of life and a reduction in depressive symptoms in people living with dementia post-intervention evidencing positive impacts from the intervention. Understanding the impacts and acceptability of singing and dancing interventions on people with dementia is important to promote accessibility and availability of beneficial support services. Evidence from this study will be used to create recommendations for future service delivery of singing and dancing interventions, with a focus on methods to make services more easily and widely accessible.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-72Fragile theatre - handling with care

Alessandro Manzella
APS Le Compagnie Malviste ETS

Since 2009, Le Compagnie Malviste has been carrying on a theatrical practice called Teatro Fragile- Handling with care. Addressed especially to people with Alzheimer's disease, it is designed to respond to the need to get them out of a condition of marginality and isolation and to allow them to enjoy a better quality of life.
The methodology of these artistic psychosocial interventions aims to create a friendly atmosphere of trust and to make the participants feel welcome and accepted. To the verbal and bodily games are added techniques from other disciplines such as dance/movement therapy, always accompanied by the musical component to stimulate the mobility. In addition, self-expression is encouraged with words - where possible - movement, singing, even using objects to awaken the physical memory.
Participants are also joined by family members or caregivers, as well as other citizens and volunteers of different ages. Our experience has shown how important and winning is the combination of bringing together and staying together, carrying out a collective work where differences, definitions and stigma fade until they disappear. In this way, the significant values and the precious contributions of each individual can emerge.

Over the years, different projects led to stage performances in pubs, bars, theatres, cultural halls, private and public parks, giving increasing importance to the intergenerational aspect that has led to the involvement of schools of all levels, including the university, on the territory. This allowed us to understand the importance of the relationship between people, to get out of loneliness and to confront each other. The aim is to awaken and to strengthen the sense of belonging to a group and the theatre is precisely the action that creates the relationship.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-73Cognitive rehabilitation for people with dementia – the Norwegian pilot for GREAT CR

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People with dementia often assume that there is little they can do when their cognitive decline starts affecting functioning. A research team led from the University of Exeter, UK, have developed a cognitive rehabilitation approach (GREAT CR) for people with dementia. The GREAT CR randomized controlled trial showed that people with mild to moderate dementia who received targeted cognitive rehabilitation experienced better functioning in activities they themselves had defined as both important and challenging (Clare et al., 2019). This pilot, done in cooperation with the UK research team, tested GREAT CR in the Norwegian municipality healthcare setting, to gather evidence about how to adapt the method to Norwegian conditions. Six health care personnel who work as case managers for people with dementia in four municipalities participated. Training was done partly with material translated into Norwegian, and partly with the English-language e-learning course. Monthly digital group supervision was provided by the UK team.
The case managers applied GREAT CR for twelve people with dementia from their caseloads. Participants, carers, and case managers were interviewed about their experiences, and quantitative data about goal attainment was collected from all three groups.
The results from all groups indicate that the approach is useful and helps improve functioning. The participants felt more independent and became more confident. However,

the approach was time consuming for the case managers, which left less time for other clients.
Rehabilitation interventions that increase independence may be of great importance both for quality of life and the opportunity to manage independently at home. We are now looking into more sustainable ways to organise cognitive rehabilitation in Norway, so that the intervention can be offered more widely within the limits of the services.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-74The efficacy of dyadic interventions for community-dwelling people with dementia and their caregivers: a systematic review and meta-analysis

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Background: Most people with dementia live at home and depend on informal caregivers for care. Both caregivers and persons with dementia can experience negative psychological and behavioural effects as the disease progresses. Non-pharmacological interventions can alleviate these effects and dyadic interventions, involving both caregiver and person with dementia, may be particularly effective.
Methods: In this systematic review, the effect of dyadic interventions involving community-dwelling persons with dementia and their informal caregivers was researched. This article is an update of a review of dyadic interventions up to 2012 (Van 't Leven et al., 2013). Twenty-two randomised controlled trials published between January 2012 and March 2023 met eligibility criteria, representing 3857 dyads.
Results: Results of the meta-analysis showed no overall intervention effect. Thirteen studies reported positive intervention effects, primarily on quality of life and neuropsychiatric symptoms, 9 studies reported no intervention effects. Intervention content, participant characteristics and knowledge of the disease varied widely between the studies reviewed. Interventions that were most effective were those that tailored activities for person with dementia to their interests and abilities, while educating the caregiver on dementia and communication. Interventions of moderate length (3-4 months) tended be more effective than longer or shorter interventions.
Conclusion: Recruitment strategies should take symptom severity and specific needs into

account, as these can influence intervention efficacy. Future research is needed to explore the factors contributing to the effects of dyadic interventions.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-75The usefulness and acceptability of a quality of life scale for carers of people with dementia: findings from an implementation study in carer support organisations

Gary Fry, Sahdia Parveen, Jan Oyebode
University of Bradford

SIDECAR (Scales In Dementia CARer quality of life) comprises a needs-led set of gold standard Rasch-scaled measures of quality of life of dementia carers.
This study supported the implementation of SIDECAR in carer support organisations. Four carer support organisations participated. Each developed an implementation plan to identify how they planned to use SIDECAR within the context of their existing structures and values. Some used SIDECAR primarily to identify family or friend carers in need of tailored support to improve their quality of life; others used it to gather data about referrals or effectiveness.
At both the start and end of the one-year implementation period, the research team conducted focus groups with organisation staff (approximately 35 at both time points) and carers (approximately 25). The study identified perceived barriers and facilitators to SIDECAR use and its usefulness and acceptability within community carer support organisations. This oral presentation will present findings on its usefulness and acceptability, as well as outlining the resulting implementation toolkit.
Staff experienced some challenges when starting to use SIDECAR, such as fitting it into workloads, understanding its purpose, and modifying existing practices to accommodate it. In some cases, these had been addressed by staff training and regular meetings, commonly emphasising the flexible way staff might use the questionnaire. Although SIDECAR was occasionally thought to lack nuance and to involve challenging questions, many staff became more confident with practice and felt they had learned more about carers and dementia. Carers themselves welcomed the way SIDECAR helped them to realise that they needed to make more time for themselves, allowing them to provide more effective care. On the basis of these and other findings in the study, a toolkit in the form of a web-based

resource has been developed to support other organisations to integrate SIDECAR into their practices.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-76How can we improve personal care assistance for people living with dementia to reduce refusals of care? A realist synthesis

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Background: As dementia progresses, people living with it develop considerable needs for assistance with personal care activities such as washing, dressing, and going to the toilet. Sometimes personal care assistance is not acceptable to the person, and they refuse care. This can be distressing for caregivers and for the person living with dementia. We aimed to find out what interventions or strategies work to reduce refusals of care, how, for whom, and in what circumstances.
Methods: We conducted a realist synthesis. Initial programme theories were developed from a secondary analysis of qualitative interview and observation data, known relevant literature, and team discussions. We then searched databases for articles providing evidence to support or refute our theories, and to add further theories. Using self-determination theory to inform and guide our work, we developed an evidenced-based framework for ways to improve personal care assistance and reduce refusals of care for people living with dementia. Stakeholder input was sought to refine the framework.
Results: Findings indicate that caregivers need to make personal care activities feel manageable for the person with dementia, the person should feel a connection with caregivers, and the degree of autonomy the person with dementia has over the care activity is important. Additionally, although comfort cannot be guaranteed, the emotional and physical comfort of the person with dementia are essential goals for care assistance, and levels of understanding of, and connection to, the care activity are valuable considerations.
Conclusion: Our findings provide practical and theoretical guidance for those interested in, or providing, personal care assistance to people living with dementia. Findings suggest multiple strategies and causal mechanisms which paid or unpaid caregivers may find helpful to improve caregiving approaches. The evidenced-based framework has relevance for those

developing psychosocial interventions aiming to improve personal care assistance for people living with dementia.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-77Comprehensive implementation of non-pharmacological interventions in German fully inpatient nursing homes as part of the “positive care” project

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Korian Deutschland GmbH

Target group(s): People in need of care living in nursing homes (with and without dementia); social care staff
Project content: Over a period of four years, seven non-pharmacological interventions were implemented in over 200 fully inpatient nursing homes. When selecting the interventions, care was taken to cover the areas of mobility, behavior, and cognition in order to be able to use targeted interventions in all areas to maintain and promote existing abilities. The aim is to maintain independence for as long as possible and to promote the well-being and quality of life of the nursing home residents. The following seven non-medical interventions are used: Formacube, Silverfit 3D, tablet with the Media4Care app, Vertellekes, memory journey, 10-minute activation & strength and balance training. As part of the implementation process, all facilities were equipped with the necessary materials and employees were trained as part of an implementation training and since then (to ensure sustainable implementation) in regular training sessions. The quality management manual contains all accompanying documents for the use of the interventions: standards for all seven interventions, Positive Care Concept, documentation notes and a FAQ. In addition, training videos for all non-pharmacological interventions are available in the Media4Care app and in an internal information portal.
Results of the project: The centrally coordinated, comprehensive implementation of seven non-pharmacological interventions in over 200 German nursing homes. At the moment, 1/3 of all residents receive at least one non-pharmacological intervention. To improve the continuity of the project, a quantitative survey on the use of the non-pharmacological interventions and a qualitative survey of social care staff (in cooperation with Coburg University of Applied Sciences) were carried out in order to identify opportunities and challenges in the facilities.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-79"IntegralMente" project, in the Pinerolese area, Piedmont, Italy

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[1]Diaconia Valdese, [2]ASL TO3 Piemonte, [3]Consortium CISS Pinerolo

The Pinerolese territory (Piedmont, Italy) includes city and mountain areas, has 130,000 inhabitants, 45,000 over sixty, often isolated and far from services. In this context, a working group on dementia has been active since 2017, which includes public bodies in the health and social sector, non-profit social bodies and families, from whose reflections the IntegralMente project was born. Given the scarcity of services for people with dementia and Parkinson's after diagnosis and the consequent fatigue of families, the objectives of the project are to integrate existing activities for the initial phases (diagnostic/therapeutic-pharmacological field, residential and semi-residential structures, home services, Alzheimer's cafés, self-help groups, dementia friendly communities projects, awareness meetings for the population, days memory assessment) with specific stimulation, support and sociability activities that also act as secondary prevention; improve quality of life; promote cognitive and relational stimulation; support families and bring them closer to social and health services; delay and reduce institutionalisation; keep people at home, and reduce loneliness.
The project activities are: cognitive stimulation; dementalent projects; movement groups; psychosocial groups; targeted home-based OSS interventions; psychological support for families; home occupational therapy.
In the first two years of activity, 199 people were taken care of (83% dementia, 17% Parkinson's), another 71 were referred to other social and health services. The results are evident in terms of proximity to health services (69% not known by public services), early diagnosis, synergy with the territory, the public/private socio-health sector and with the world unrelated to services. Furthermore, the activities allowed families to form a common front, to feel accompanied, thus decreasing their sense of isolation.
For the near future we intend to incerase cognitive stimulation activities and design training courses for family assistants/caregivers, and to repeat he "path of adaptation" to rhe didgnosis for newly diagnosed people with Parkinson and their families.

Dementia researchers of the future: Innovative approaches to dementia

POS1. Posters - Patient pathways

POS1-80Caregivers and technology: a qualitative perspective

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The responsibility of caregiving largely relies on the immediate family or closest relatives. In fact, 80% of persons diagnosed with Alzheimer's disease (AD) rely on the care provided by their family members. Caregivers may have different and changing needs over time when it comes to technology support.
From the Pasqual Maragall Foundation, Spain, we implemented several resources to promote the engagement of caregivers of persons with Alzheimer, including direct mails and telephone calls. Furthermore, group sessions (4 groups, n=xx per group) were conducted to gather the concerns and knowledge of caregivers on technology related to lifestyle experience with AD. The following topics were covered in the focus groups: (a) experience with the use of technology, (b) daily experience in informal caregiving, (c) reflections on perceived needs as caregivers, and (d) services that could be useful and provided through a technological mean.
The sociodemographic profile of the sample (n=22) consists of caregivers aged between 71 and 80 years, with a significantly higher representation of women (63,6%) compared to men. The majority of participants self-assess their technology usage between an intermediate and advanced level. The most prominent category of limitations and risks is their concern about security regarding privacy and data protection.
For the design of interventions and technological developments it is fundamental to consider generational differences and the variety of technological skills to optimize the usefulness and acceptance of these tools with a co-creation process with caregivers and individuals living with AD.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-81Rooted in nature: exploring the potential of outdoor spaces to enhance living well with dementia at home

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Research Group Living Well with Dementia, Windesheim University of Applied Sciences

Background: Research indicates that nature and nature-based interventions enhance the quality of life for people with dementia. However, much of this research concentrates on people attending adult day care facilities or living in nursing homes. Significantly less is known about the potential of nature-based interventions at home. The aim of our study was to explore the potential of integrating nature into the daily lives of people with dementia who live at home. Additionally, it aimed to identify competencies and skills required for social workers to incorporate nature into their working routines.
Method: In a qualitative study using a double diamond design - located at a social work organization - we organized walking interviews with people with dementia and interviews with informal caregivers and social workers. In two focus groups with people with dementia we explored the meaning of nature and gathered ideas for nature-based activities. We thereby used photo-cards depicting nature and nature-based activities. We additionally organized creative sessions with social workers to identify challenges and opportunities to work with nature.
Results: The interviews revealed that nature brings peace, quietness, and distraction from stimuli to people living with dementia. However, they are seldom exposed to nature. Their loved ones often encourage them to stay indoors due to fears of falling or getting lost. People with dementia experience uncertainty about going outdoors. Social workers acknowledge the importance of nature, but express a lack of knowledge and skills to offer or refer to nature-based interventions .
Conclusions: There are opportunities to improve access to nature for people with dementia in their daily lives. In the next phase of this study, we will co-create a nature-based intervention with people with dementia and social workers. Additionally, we will develop various knowledge products to inspire social workers to integrate nature into their work.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-83Positive approach to care (PAC): a realist evaluation study

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There is a need to increase availability of evidence-based psychosocial interventions to improve the care of those living with dementia. As the cognitive and functional abilities of a person living with dementia change, their ability to e.g. eat or wash may decline, and these tasks require support from a caregiver. This project is assessing the use of a model of care - Positive Approach to Care (PAC) in UK dementia care settings.
A key intervention of the PAC model is Hand-under-Hand® (HuH; Snow, 2012). Developed by occupational therapist Teepa Snow (see https://teepasnow.com/), this technique aims to assist people in all areas of engagement, especially with activities of daily living, with the caregiver's hand performing the activity, which the person living with dementia's hand rests on top of the caregiver's palm-to-palm. This technique is theorised to elicit fewer problems with people living with dementia where their brain is unable to process the movement (see e.g. Amellia, Aselage, 2012; Batchelor-Murphy et al. 2015), with a relationship-based connection in HuH eliciting less threat-related neural activation as a function of the social regulation of emotional responding in the face of various stressors such as getting touched by another person during intimate ADL care (Coan et al, 2006).
This is the first study to evaluate PAC in UK dementia care settings. A realist evaluation is being used to identify contexts, mechanisms and outcomes that support the use of PAC. Mixed methods will be used to assess dementia knowledge and perception, carer burden and sense of competence, and experience of PAC. The project will develop an initial programme theory (IPT) using a realist synthesis of literature. The IPT will then be tested in care environments, followed by development of a programme theory. The theory developed will be used to inform future development of PAC in dementia care.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-85How can professionals support family caregivers in experiencing more calmness in their daily life with a person living with dementia?

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Introduction: There is increasing evidence on the beneficial effects of psychosocial interventions for family caregivers. Processes contributing to these changes are more rarely explored. Such information is essential to develop and fine-tune interventions to address the specific needs of different family caregivers during the different stages of their caregiver journey. The psychoeducational intervention "Learning to feel better and help better" has shown promising results regarding caregiver burden, self-efficacy and distress. However, more knowledge is needed on the processes contributing to these changes as well as on intervention components promoting beneficial processes in caregivers.
Methods: Change processes were explored with a secondary data analysis of longitudinal and cross-sectional qualitative interviews performed with 22 caregivers participating in the "Learning to feel better and help better" intervention.
Findings: The main change reported by caregivers was experiencing calmness, which was facilitated by caregivers being able to manage their daily life, facilitate positive interactions with their family members with dementia, have confidence in their capacities to fulfil their caregiver role and find a balance between their own needs and caregiving demands. Active skills training was essential to empower caregivers to become more responsive while managing their daily life and changes in their relationship with the person with dementia. Sharing experiences and knowledge in a group with other caregivers and healthcare professionals helped caregivers to better acknowledge and tailor their caregiver role while respecting their capacities and needs. Caregivers struggling to accept dementia-related changes may need individual support specifically designed to cope with their grief process.
Conclusion: Caregiver empowerment requires not only knowledge on dementia, but also active skills training to effectively apply such knowledge in daily life. Opportunities to share experiences and expertise with other caregivers and professionals can promote positive carer role development.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-86METHODEM: Methodological consensus for complex interventions in dementia

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Background: The UK Medical Research Council (MRC) framework (Skivington et al., 2021) has synergies with views of dementia researchers that psychosocial interventions should be designed, tested, and evaluated based on both theoretical frameworks and implementation considerations. Yet, dementia-specific evidence synthesis concerning 'if and how' the MRC is applied is lacking. Moreover, stakeholders' (i.e., multi-disciplinary researchers, health/social care staff, policy makers, people affected by dementia) views on (novel) methodologies and designs have not been explored.
Objective: The METHODEM project includes two complementary studies and has the aim to i) provide a comprehensive overview of novel and commonly used designs and methodologies for research on complex psychosocial interventions in dementia care (Study 1) and ii) reach a consensus on which designs and methodologies a) integrate the core elements of the MRC framework and b) suit the objectives of each project phase (Study 2) (i.e., which design/ methodology is suitable when, how, and why).
Methods: This project is executed by the Methodology Taskforce of INTERDEM and starts in July 2024. In study 1, we will systematically review and synthesize evidence on methodological approaches for complex interventions in dementia care (peer-reviewed studies published since 2000), and in study 2, we will transform expert opinions into a group consensus using a multi-phase Delphi design.
Results: The METHODEM project will present methodological trends, gabs, strengths, and limitations of methodologies, and result in consensus-based recommendations for future studies.
Conclusion: Gathering, discussing, and disseminating evidence on current research practices and future directions for methodology in psychosocial intervention dementia research is relevant, not just within academic contexts, but especially for their societal implications. The outcomes of METHODEM can help strengthen the quality, understanding and recommendations for research on psychosocial interventions, thereby reducing the gap between research and practice and improving the lives of people affected by dementia.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-87What happens when a busy, enthusiastic, doctor-daughter is unexpectedly thrown into caring for her estranged father when he was diagnosed with Alzheimer's dementia?

Helena Popovic
Outwitting Alzheimer's

After unexpectedly finding a box of rivastigmine in the butter compartment of my father's fridge, I started piecing together that he'd been diagnosed with Alzheimer's. My mother had recently passed away with lung cancer and I'd attributed his withdrawal and cognitive decline to grief. Thus began our adventure with dementia. Over the ensuing decade, my all-consuming mission to slow his disease progression and provide him with the best care led to a discovery I did not expect: dementia need not be a disaster or a dread. Instead, it can be a doorway to creating a healthier brain, stronger body and more fulfilling life. At the age of 78, I bought Dad his first-ever gym membership, his first pet dog and his first iPod. Meticulously working our way through the 12 modifiable risk factors listed in *The Lancet* in July 2020 (smoking, low education, head injury, type 2 diabetes, hearing loss, hypertension, social isolation, physical inactivity, high BMI, alcohol and air pollution) and adding sleep hygiene, forest bathing, wild salmon, curcumin, B12, raw cacao and volunteering to the mix, our story demonstrates that education is more powerful than medication, and outwitting Alzheimer's is within our reach. Above all, my experience shows that the most significant factor in slowing Dad's decline was maintaining his sense of meaning, purpose and contribution. As long as his brain had a reason to keep functioning, it did. As long as he felt valued and of value, he found it inside himself to keep going and to maintain his cognitive functioning. In many ways, my case study of Dad is also a thank you letter to everyone attending 34AEC Geneva. Without their groundbreaking work and exchange of insights, I wouldn't have had the courage to take on the daunting role of becoming my father's care-partner.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-88The power of gratitude and breath work in reversing cognitive decline

Helena Popovic
Outwitting Alzheimer's

Researchers at University College London found that repetitive negative thinking (RNT) — known as perseverative cognition — can change the structure of our brain and increase the risk of Alzheimer's. A study of 350 men and women over the age of 55 revealed that those who habitually criticised themselves, focused on regrets, ruminated about past failures, and worried about the future had greater decline in memory and thinking skills than people who were more positive and optimistic. The ruminators also had higher amounts of amyloid beta (Aβ) plaques and neurofibrillary tau tangles in their brains. The key word is 'repetitive'. Everyone sometimes feels despondent, but if it becomes a person's default mode of thinking, pessimism erodes brain function. This is an astonishing finding: our thoughts have a physical impact on our brain. Toxic thoughts produce toxic molecules.
This has led to the Cognitive Debt Hypothesis: persistent negative states of mind induce a chronic stress response that erodes brain function. The mechanisms through which stress promotes neuronal death involve reduced brain blood supply (cerebral hypo-perfusion), increased inflammation, and the hormone corticotropin release factor (CRF). CRF can directly bind to cells in the hippocampus and trigger phosphorylation of tau proteins, which leads to accumulation of neurofibrillary tangles. Negative thinking also depletes the brain of energy and leaves it with less fuel for other tasks. Hence memory, focus and cognition can all begin to suffer.
These findings are NOT about blaming people for having negative thoughts or forcing ourselves to be positive when we don't feel it. On the contrary, it's about empowering people to implement two simple antidotes to RNT that can independently reverse cognitive debt: gratitude exercises and breath work. This presentation shows how simple daily gratitude practices and five minutes of specific breathing techniques can reduce Alzheimer's pathology and enhance cognition.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-89Truth, comfort, and connection: what couples with dementia seek during reality disjunction

Yvon Ruitenburg, Yvon Ruitenburg, Minha Lee, Panos Markopoulos,

Wijnand Ijsselsteijn
Eindhoven University of Technology

Communication can become challenging for people with dementia due to language, speech, discourse, and memory impairments. Through interviews with 16 people with dementia, 14 formal caregivers, and 6 spouses, we found that communication challenges can lead to people with dementia presenting a different reality in their interactions than is experienced by others. Couples with dementia may experience reality disjunction, where they both present contradictory worldviews as true when memories are forgotten, altered, fabricated, or ineffectively conveyed. Consequently, people with dementia may not be believed for their described experiences, and couples feel frustrated and disconnected when attempting to realign their diverging realities. In interviews with six couples with dementia, we found that the people with dementia and their spouses' responses to reality disjunction depended on what they valued in the interaction. When they valued truth, they contradicted each other's statements to maintain personal truth, protect their partner from harm, or keep their partner in their reality. When prioritising comfort, they would let go of the reality disjunction by ignoring, distracting, or going along with it to avoid distress, effort, or discussions. When they sought connection, they empathised with their partner's recollection to increase communication, mutual understanding, and respect for their partner's epistemic rights. Using speculative designs, we also examined how conversational technologies like Alexa could help these six couples with dementia manage reality disjunction. Results show that conversational technologies could help them check and communicate memories, reduce distress, and practice different responses to reality disjunction. Future research should explore strategies and conversational technologies for couples with dementia to uphold truth, comfort, and connection during reality disjunction. These efforts are crucial for supporting their relational and psychosocial well-being.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-90Implementation of MAKS, a systematic group program for people with dementia in in Norway – a pilot study

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Tailored services and activities that contributes to promotion of health and quality of life for people with dementia are important. In Norway, providing day care for people with dementia is a national priority. The purpose of day care is to facilitate social inclusion and participation in activities. But studies show that there is a potential to use activities more to promote health and quality of life. In this project, a systematic group program for people with dementia living at home, will be piloted within the day care. The program is called MAKS and was developed at the University of Erlangen, Germany. MAKS is multicomponent intervention composed of four parts as motor stimulation, performance of activities of daily living, cognitive activation, and social-communicative component.
Aim: To adopt, implement and evaluate MAKS, delivered at day care for people with dementia living at home to enhance quality of life and maintain levels of physical, social, practical, and cognitive functioning.
Methods: First, the MAKS protocol and program will be translated into Norwegian. Second, to gather experiences on the feasibility of MAKS, a pilot study will be conducted in invited Norwegian municipalities. Finally, how the intervention is perceived and how it affects the participants will be collected during and after a 10-month intervention period. The project is carried out in collaboration with the Norwegian Health Association (NHA). NHA are responsible for the inclusion of activity buddies/volunteers who can contribute in the MAKS groups.
Results: This is an ongoing project, thus there are no currently available results. To date, four day care services from four municipalities are recruited. First impressions, the staff at the recruited day care are enthusiastic about piloting MAKS and collaborating with the project group to learn about MAKS and determine which activities should be selected for use in the pilot intervention.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-91Therapeutic doll interventions for people living with dementia: a scoping review

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Background: Doll therapy is a psycho-social intervention that has been commonly used within dementia care for many decades. The practice of doll therapy involves supporting people with dementia to engage with a therapeutic doll and this has been associated with positive changes in a person's wellbeing and behaviour. While there have been several systematic reviews that have focused on behavioural outcomes, limited reviews have explored the broader psychosocial outcomes associated with doll therapy
Methods: A scoping review of the literature was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-analysis extension for ScR (PRISMA-ScR). Four electronic databases were searched systematically (CINAHL Plus, Medline, PsycINFO and PubMed). A mixed Methods appraisal tool (MMAT) was used to assess the quality of primary studies, however, all relevant studies were considered regardless of their methodological quality. The 'Population-Concept-Context' framework was used in the screening process to identify eligible papers.
Results: 12 primary research studies from the past ten years (2013-2023) were included in this review. Primary data was synthesised using a narrative synthesis methodology. There three main things from this review relate to 1) the extent to which doll therapy can enhance quality of life in people living with dementia, 2) the impact doll therapy can have on verbal and non-verbal communication between people living with dementia and their caregivers and professional staff, and 3) the potential for doll therapy to reduce associated caregiver distress.
Discussion: Doll Therapy has progressed as a person-centred intervention that has potential to enhance quality of life in people with dementia, building quality relationships between people with dementia and caregivers/ professionals. It is a cost-effective, evidence based, least restrictive intervention that can be used within dementia care settings.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-92Professionals' learning and development needs for improving quality of life in dementia: findings from the SPREAD+ consortium

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Numerous psychosocial interventions supporting quality of life in dementia are currently available. However, these interventions are insufficiently adopted in practice and education. Among others, this is due to the fact interventions are poorly tailored to professionals' learning and development needs and practical context.
The SPREAD+ consortium is a collaboration of Dutch research institutes aiming to (further) develop and implement interventions supporting quality of life with dementia. Doing so requires understanding dementia professionals' learning and development needs and everyday work situations. We have therefore conducted a qualitative study into the learning and development needs of (future) professionals. Data collection consisted of interviews and focus groups with sixteen professionals (e.g. nurses, physicians, social workers) and eight educators (teachers in nursing and social work programs, learning and development policy advisors in organizations providing care and support for older people).
Our study demonstrates that most professionals viewed learning and development as formal processes occurring in the context of various educational programs. However, their descriptions of their everyday work reveals that learning and development in fact also take place informally and continuously in practice. Professionals' learning and development needs mostly revolve around solving practical problems. These include dementia-specific dilemma's (e.g. challenging behavior, crises) and navigating a complex care system. Meanwhile, professionals' real learning and development opportunities are determined by the formal and informal 'learning paths' afforded by organizations. Finally, professionals indicated that they increasingly work together with various stakeholders (other disciplines, family members), but that such collaborations can be challenging. This implies that learning to collaborate effectively is an important learning and development need in dementia care and support. With this study, we aim to contribute to the development of well-tailored psychosocial interventions for quality of life with dementia, which is a precondition for timely, effective, and sustainable implementation.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-93Comparative study between young caregivers and adult caregivers: the issue of support

Sara Trolese, Ilaria Chirico, Marco Brigiano, Giulia Despini, Martina Quartarone, Rabih Chattat

Background: Young informal caregivers provide voluntary, unpaid assistance to family members with illnesses or disabilities. While some derive benefits from caregiving, such as increased self-esteem, maturity and empathy, others are exposed to psychological, physical, and social health risks.
Aim: Two studies aimed to: 1) profile young adult caregivers (aged 18-30) and compare them with adult caregivers (aged 31-64) regarding subjective burden, psychological well-being, perceived social support, coping strategies, and family functioning; 2) systematically review psychosocial interventions targeting adolescent and young adult caregivers, including barriers and facilitators influencing intervention implementation.
Methods: An online survey collected data using Zarit Burden Interview, The Psychological General Well-Being Index, The Multidimensional Scale of Perceived Social Support, The Coping Orientation to Problems Experienced Inventory, and The McMaster Family Assessment Device. A systematic review analysed 8 articles on psychosocial interventions for young caregivers.
Results: The survey revealed several risk factors among young caregivers, including high subjective burden, psychological distress, anxiety, avoidant coping strategies, and dysfunctional family functioning. Compared to adults, young caregivers experienced a higher subjective burden, worse general health, more use of avoidant strategies, and increased dysfunctional family functioning (i.e., problem solving, affective responsiveness). Thematic analysis identified 3 different themes: intervention strategies, difficulties in accessing and using services, and intervention delivery preferences among young caregivers.
Conclusions: Performing care-giving tasks at a young age induces burdens and psychological distress. Young caregivers often lack internal family resources and effective coping skills. Identifying this population and implementing evidence-based interventions are crucial to prevent long-term health consequences for young caregivers.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-94The cognitive daisy (COG-D): exploring the feasibility of implementation in care homes

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Person-Centred Care (PCC) is a crucial part of dementia care in care homes. Knowledge about a resident's unique cognitive profile is acknowledged in best-practice models of PCC and is considered core knowledge for care staff, yet in practice it remains an overlooked area of dementia care. The Cognitive Daisy (COG-D) is a novel tool that provides a visual summary of an individual's cognitive profile in the shape of a flower. This acts as a visual prompt to remind care staff of the resident's cognitive problems and respond in line with individual needs in the moment. Here we report the findings of a feasibility cluster RCT, involving 105 recruited residents and 99 care staff in 8 UK care homes. The primary objective was to explore the feasibility of investigating the implementation of COG-D on a large scale in care homes. Care homes were randomised to the intervention arm or the 'usual care' arm. During the intervention residents were assessed using the COG-D neuropsychological assessment at the start of the intervention phase and 6 months after. Daisies (created with assessment scores) were displayed in residents' rooms and in their care plans. Care staff completed the Basic training (how to use the Daisies) or the Advanced training (how to conduct the COG-D assessments). Outcome measures for residents and staff were obtained at baseline, and 6- and 9-month post-randomisation. Key feasibility criteria, i.e., recruitment of residents and staff, completed COG-D assessments, and completed staff training, were found to be in the acceptable range. A process evaluation (including care plan audits, huddles and follow-up interviews or focus groups) was conducted to explore acceptability, fidelity, and adherence to the intervention. Potential signals of effect in outcome measures will be discussed with consideration of perceived facilitators and barriers to implementation of COG-D in care homes.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-95Novel designs and methodologies for complex psychosocial interventions in dementia

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Background: Several frameworks and guidelines have been published to guide the development and evaluation of complex interventions. The UK Medical Research Council (MRC) framework is a widely cited source, outlining the core components (e.g., intervention context, stakeholder involvement, programme theory) and stages (i.e., development, feasibility/piloting, evaluation, and implementation). Its updated version (Skivington et al., 2021) proposes a pluralistic approach and methods, extending beyond efficacy and effectiveness to emphasise understanding underlying mechanisms of change, societal impact, and intervention sustainability. However, despite these advancements, there appears to persist a predominant reliance on Randomised Controlled Trials (RCTs) for evidence. RCTs often overlook contextual factors and the dynamic complexities in dementia care settings, thus limiting insights into the mechanisms underlying changes. While new methodological approaches are emerging, it is unclear how they match the MRC framework objectives and address its core elements.
Aims: This opinion work aims to reflect on the MRC recommendations and provide examples of emerging approaches integrating MRC core elements in the development and evaluation of psychosocial interventions in dementia care.
Methods: Research designs and methodologies for psychosocial interventions in dementia, as discussed by the INTERDEM methodology taskforce expert group at meetings, conferences and webinars, were reviewed in relation to the MRC core elements.
Results: Viewed through the current MRC framework lens, a collection of existing and novel designs and methodologies (e.g., Realist evaluation, Participatory research approaches, Pragmatic Trials) within the growing field of psychosocial interventions in dementia were identified and discussed. Critical reflections were drawn from various dementia research projects.
Conclusions: The identified designs and methodologies for complex psychosocial interventions in dementia care showcase research approaches that adhere to several core components of the MRC framework. The aim is to stimulate debate and best practice in the field, further enhanced by an upcoming opinion article.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-97Development an e-learning program on emotions, breathing, mindfulness and sleep in young onset dementia (YOUNG-D)

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Background: Young onset dementia (YOD) often goes along with increased stress and sleep problems, which affects heart rate variability and quality of life. Relaxation exercises such as breathing and mindfulness have been described to help cope people with these issues. However, caregivers don't always know how to handle emotional distress and questions regarding relaxation or sleep problems when they occur during their caregiving for people with YOD. Furthermore, caregivers don't always feel skilled or secure to provide these relaxation exercises themselves to people with YOD.
Methods: In 2021, researchers at Odisee University of Applied Sciences (Brussels, Belgium) designed a behavioural program (JONG-D) in co-creation with YOD care providers in Flanders. This program was intended for people with YOD to provide tools and coping mechanisms regarding stress and sleep management. Based on a co-creation process with seven European care and educational partners, an integrative YOUNG-D program was designed to provide caregivers an accessible program to help people with YOD with emotional distress and sleep problems (co-funded by the EU Erasmus+ program). Based on the YOUNG-D program, an e-learning was developed to help caregivers and students gain insight in the possibilities of breathing and mindfulness techniques as tools to cope with emotional distress and sleep problems in YOD.
Results and conclusions: An e-learning was developed and provided to help caregivers and students understand the interplay between YOD and feelings, emotions and sleep as well as the application of relaxation techniques such as breathing and mindfulness in YOD. Experiences in the development of the e-learning as well as the practical implementation will be discussed.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-98Effects of a music therapy and music listening intervention for nursing home residents with dementia: a randomized controlled trial

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The aim of the present study was to evaluate the effects of an individual music therapy intervention and an individual music listening intervention on neuropsychiatric symptoms and quality of life in people with dementia living in a nursing home and on professional caregiver's burden to be able to make statements about their specific value of application in clinical practice. A multicenter single blind randomized controlled trial with three groups (N = 158) was performed: an individual music therapy intervention (IMTI) group (n= 49), an individual music listening intervention (IMLI) group (n = 56) and a control group (n = 53) receiving usual care. The interventions were given during three weeks, three times a week on non-consecutive days during 30–45 minutes for in total nine sessions. Endpoints were the difference from baseline to interim (1,5 week), post-intervention (3 weeks) and follow-up (6 weeks) in reported scores of problem behaviour (NPI-NH) and quality of life (Qualidem) in people with dementia and occupational disruptiveness (NPI-NH) in care professionals. Multilevel analyses demonstrated that hyperactive behaviour assessed by the NPI-NH was significantly more reduced for the IMLI group at follow up and that restless behaviour assessed by the Qualidem was significantly more reduced for the IMTI group at post and follow-up measurement compared to the control group. No significant effects between groups were found in other NPI-NH clusters or Qualidem subscales. In conclusion, because we found no convincing evidence that the IMTI or IMLI is more effective than the other both interventions should be considered in clinical practice.

Patient pathways - Psychosocial interventions

POS1. Posters - Patient pathways

POS1-99Improving the quality of life and social participation of people living with dementia in shared-housing arrangements - results of the DemWG study

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For people living with dementia (PlwD) aspects of social health such as social contacts and participation in social activities as well as related aspects of quality of life (QoL) are becoming increasingly important in research and practice. In Germany, specific living models such as Shared-Housing Arrangements (SHA) enable PlwD to be involved in social, movement-related, sensory, cognitive and creative activities. The DemWG study addresses two questions: 1) To what extent did social activities take place in SHA during the Covid-19 pandemic? 2) How does a movement and cognition-related intervention (MAKSmk+) affect aspects of social health and QoL in PlwD? The DemWG study took place as part of a longitudinal cluster-randomized, controlled and prospective mixed-methods study from April 1, 2019 - December 31, 2022. In addition to standardized assessments, expert interviews (n=13) and focus groups (n=2) were carried out. QoL was assessed using QUALIDEM, a dementia-specific external assessment instrument. A variety of regular social activities with movement-related, sensory, cognitive or creative approaches were regularly standardized assessed. Nationwide, 97 SHA with 341 PlwD participated at baseline. Within the complete longitudinal study, data from 236 participants were evaluated. The most frequently offered and used activities by PlwD in SHA are entertainment and shared social activities (2020: 76.54%, 2022: 87.9%), followed by movement-related activities (2020: 75.88%, 2022: 77.8%) and sensory activities (2020: 49.56%, 2022: 47.0%). Despite some declines at the beginning of the Covid-19 pandemic, social activities are attended regularly in SHA. During MAKSmk+ use, increased social interaction between nursing staff and residents was reported in focus groups and expert interviews. A longitudinal regression analysis for the QUALIDEM-total-score showed both, a statistically significant increase in QoL during the intervention and a significant difference between the frequencies of MAKSmk+ use. The results indicate that MAKSmk+ should be integrated into everyday care, especially with regular use.

Policy - Dementia strategies

POS2. Posters - Policy

POS2-01Multi-Disciplinary Team working and developing a dementia pathway: An Island perspective

Jeanette Hogg
Hospice Isle of Man

Background: Approximately 1600 people locally with a dementia diagnosis. Three key partners involved. Historically no joint working or sharing information. Caregivers unsure

who to call and who is responsible for what part of the journey. Lots of overlap and duplication.
Aims: To improve Multi-Disciplinary Team (MDT) working and person centred care
To ensure caregivers and PLWD know who has responsibility for each part of the dementia trajectory
Methods: Monthly link meeting between partner agencies. Sharing ideas and best practice, service developments and updates.
Stream lining processes, referrals, training and caseload management
Caseload reviews
Dementia Awareness Week
Results: Case studies – when it goes wrong / when it works well.
Steering group to inform working practice and share information.
Dementia Awareness week – multi-disciplinary annual roadshow which advises the general public of the local dementia services
Development of dementia pathway and dementia ecosystem
What's on booklet
Creative Minds in Mann – therapeutic art sessions for PLWD and their caregivers.
Impact going forward: Dementia pathway to assist professionals to know when to refer to each service.
Ecosystem -given to caregivers at diagnosis or during six monthly memory assessment follow ups. Shows who is involved at each point. Positive feedback "I know who to call now"
ACP and difficult conversation training for other health professionals so they feel comfortable discussing ACP – not just end of life but around communication; mobility; falls; continence; eating and drinking
Development of a dementia strategy for the IOM. Carer Focus groups "In Your Shoes"
Link with frailty pathway / falls pathway/ Parkinson's nurse / Speech & language therapy
Limitations: Need to involve wider health and social care professionals – community and hospital; housing; government; treasury
Getting dementia recognised as both a public health priority and a palliative condition

Policy - Dementia strategies

POS2. Posters - Policy

POS2-02Implementing dementia strategies: a comprehensive approach

Nigel Hullah
EWGPWD



Dementia, a global crisis affecting millions worldwide, poses one of the most pressing challenges of the 21st century. It places a significant burden on individuals, families, and societies, necessitating the urgent attention of policymakers, healthcare professionals, researchers, and advocates to develop effective strategies to address its multifaceted needs. This abstract proposes a comprehensive approach to implementing dementia strategies beyond traditional medical interventions. Drawing on interdisciplinary research and best practices, our proposed strategy encompasses four key pillars:
Early Detection and Diagnosis: Implement widespread screening programs and promote awareness campaigns to encourage early detection of dementia symptoms. Early diagnosis facilitates timely interventions and access to support services, improving outcomes for individuals and their families.
Person-Centered Care: This involves shifting from a disease-focused model to a person-centered approach that prioritizes the individual's preferences, values, and unique needs.
Community Engagement and Support: Establishing dementia-friendly communities that promote inclusivity, accessibility, and support for individuals with dementia and their caregivers. This includes providing education and training for community members, creating dementia-friendly environments, and enhancing access to social, recreational, and healthcare resources.
Research and Innovation: Investing in research to advance our understanding of dementia risk factors, treatment options, and best practices in care delivery. Embracing innovation in technology, including digital health solutions and assistive technologies, to enhance quality of life, promote independence, and support caregivers.
By integrating these pillars into a cohesive dementia strategy, we can create a more supportive and inclusive environment for individuals with dementia, empower caregivers, and promote overall well-being. This approach, which acknowledges the complex and diverse needs of people affected by dementia, underscores the vital role of collaboration across sectors, emphasizing the shared responsibility in achieving meaningful and sustainable outcomes.

Policy - Dementia strategies

POS2. Posters - Policy

POS2-03From Plan to Impact VII: dementia at a crossroads

Lewis Arthurton, Chris Lynch, Chloé Benoist, Wendy Weidner, Paola Barbarino, Robbie Appleton-Sas, Gloria Mantineo
Alzheimer's Disease International

In 2017, Member States of the World Health Organization (WHO) unanimously adopted the Global Action Plan on the public health response to dementia, the primary objective being the global adoption of National Dementia Plans covering seven action areas. Each year since the adaption of the Global Action Plan, Alzheimer's Disease International has tracked the progress of Member States towards achieving the target of the plan through the report, 'From Plan to Impact'. The 7th iteration, 'From Plan to Impact VII: Dementia at a crossroads' was launched at the WHO World Health Assembly in May.

With less than 1 year remaining until the completion of the Global Action Plan, just 38 Member States have a functioning National Dementia Plan, falling far short of the 146 (75%) target. Presently, there are 27 countries developing dementia plans or are incorporating dementia within a wider health plan. While the European region hosts close to half of these plans (19), large gaps remain, particularly in Eastern Europe but increasingly in western Europe. Outside of Europe, the Americas hails the next largest region of plans (9), while the South East Asia Region, Western Pacific and Eastern Mediterranean regions host the remaining plans (10). No plans exist in the African region.

The report centres around Alzheimer's Disease International's and our member's call for Member States to request a 10-year extension to the Global Action Plan, highlighting its importance and necessity in light of the rising prevalence forecasts for dementia and the emergence of new disease modifying therapies. Simultaneously the report draws attention to best practice globally, charting a course for the next decade.

Policy - Dementia strategies

POS2. Posters - Policy

POS2-05Dementia Strategy in Slovenia by 2030

Štefanija L. Zlobec, Štefanija L. Zlobec
Združenje Spominčica

Spominčica has been an active partner of the Ministry of Health of the Republic of Slovenia in development of the second Dementia Strategy in Slovenia by 2030 (Dementia Strategy)

which has been adopted in 2023 by Government of the Republic of Slovenia. First Dementia Strategy has been adopted in 2016 until 2020.

The Dementia Strategy aims to:

1. to promote prevention programmes to reduce risk factors and maintain and promote health in the community
2. diagnosing the early stages of neurocognitive disorders, improving access to quality, safe and effective health care and treatment
3. improving access to appropriate and coordinated post-diagnostic interdisciplinary care for people with dementia, including integrated care, long-term care, social services, support for families or carers in the local environment and access to palliative care
4. the use of modern information and communication for the management and support of people with dementia
5. increasing respect for the dignity of people with dementia, reducing stigma and raising awareness among the general and professional public in order to create dementia-friendly communities
6. educating all professional groups on dementia management
7. establishing a national data collection on dementia
8. promoting up-to-date research on dementia
9. establishing a national dementia center
10. appropriate treatment of people with dementia during epidemics and other emergencies

At the beginning of this year, the Government of the Republic of Slovenia adopted the Action Plan for the implementation of the Dementia Strategy for the period 2024-2025, in which Spominčica plays an active role in the implementation of the prevention, awareness, reducing stigma and educational objectives of the Dementia Strategy, for which we have been provided with financial resources by the Ministry of Health.

Policy - Dementia strategies

POS2. Posters - Policy

POS2-06National survey of centers for cognitive disorders and dementias, nursing home and dementia day centers in Italy

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The Italian National Dementia Plan (NDP, 2015) includes the development of an online map of facilities for people with dementia (PwD). The Italian Fund for Alzheimer's and other dementias (2020) enabled to carry out three surveys in Italian health facilities for dementia, Centers for Cognitive Disorders and Dementias (CCDDs), Nursing Homes (NHs), and Dementia Day Centers (DDCs)
Aim: The surveys aim to report administrative features and services offered to PwD, and to provide an updated on line map.
Methods: A list of all national CCDDs, NHs and DDCs was requested for each Italian region. Three different questionnaires have been formulated to analyze: location, access, organization, services, treatments provided, and any discontinuation of the services during pandemia. The surveys were carried out between July 2022 and October 2023.
Results: Overall, 534 CCDDs, 1084 DDCs, and 3607 NHs were identified across Italy, with 96%, 41%, and 46% response rate, respectively. All responding facilities are included on the online map (https://www.demenze.it/it-mappa).
Almost half of the CCDDs operated for 3 or fewer days a week, and about one-third had at least two professional figures among neurologists, geriatricians and psychiatrists. Only 10% of the DDCs were public, half of the DDCs have fewer than 10 professional staff members. During the pandemic period, 6% of facilities were always open in 2020, while 48% were open in 2021. NHs were almost all privately owned, with a third of the beds occupied by PwD. Moreover, 60% of NHs have fewer than 50 professional staff members.
Conclusion: The geolocation of the facilities and the update on the current status of CCDDs, NHs and DDCs in Italy highlighted a significant heterogeneity in diagnosis and care of PwD at the regional level.
Project carried out with the technical and financial support of the Ministry of Health chapter-2302

Policy - Legal and ethical issues

POS2. Posters - Policy

POS2-08Involvement of informal caregivers in healthcare decision-making of older adults with dementia

Roos Nieuwboer
Vrije Universiteit Amsterdam

Introduction: Informal caregiving is an indispensable part of the Dutch healthcare system. Over the past decade, the number of informal caregivers in the Netherlands has increased by more than a quarter of a million, and the number of informal caregivers will probably increase even more due to population ageing. Informal caregivers of older adults with dementia often assist with decision-making, particularly regarding healthcare. When older adults with dementia experience a decline in cognitive abilities, their informal caregivers may find themselves into a more substantial role in decision-making. This transition could occur gradually or abruptly and potentially requiring the informal caregivers to act as representatives.
Little is known about the experiences of informal caregivers with healthcare decision-making in the Netherlands and the practical, emotional and legal challenges they may face. This study aims to provide insights into these experiences and challenges of informal caregivers of older adults.
Methods: For this study, a cross-sectional survey with both quantitative and qualitative elements was conducted, as well as semi-structured interviews with informal caregivers of older adults in the Netherlands.
Results: Results will be presented during the Alzheimer Europe Conference (34AEC), as the research will be concluded in July of 2024.
Conclusions: First conclusions will be presented during the Alzheimer Europe Conference (34AEC), as the research will be concluded in July of 2024.

Policy - Dementia work force

POS2. Posters - Policy

POS2-09Marte Meo - From your own strength - or how communication for people with dementia can be adapted to people with dementia in a simple learning setting

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Communication and interaction are often crucial to ensuring good quality care for people with dementia. This is why Domicil Bern AG has been using the image-based interaction and communication method Marte Meo® since 2014. The method is characterized by the fact that it can be learned and applied by nursing and care staff as well as by relatives and other people involved.
What does marte Meo mean?
Marte Meo means "out of one's own strength". This is also the basic approach of the method developed by Maria Aarts, Netherlands. Using film sequences from everyday life, existing resources are shown in detail by all participants in interactions. In this way, existing skills can be used more consciously, strengthened and maintained.
Effect of Marte Meo: Simple and concrete communication elements, which are used consciously, are decisive for whether a connection can be established between people and the quality of this connection. It can also influence and support the willingness to cooperate and joint action.
A fleeting moment can be captured with the help of the film sequence. The joint focus on the sequence experienced and the joint visualization help to better understand the situation.
People with dementia in particular need a counterpart who is at eye level, adapts the pace to them and can enter their world. Marte Meo helps to support caregivers in this demanding work and people with dementia receive communication that is adapted to them.

Policy - Dementia work force

POS2. Posters - Policy

POS2-10Confident conversations: Developing an online learning module for Admiral Nurses in support of recruitment of people living with dementia to research

Karen Harrison-Dening[1], Karen Harrison Dening[1], Jessica Roebuck[2], Emma Wolverson[1], Amy Pepper[1]
[1]Dementia UK, [2]Join Dementia Research

Dementia research, such as clinical trials and qualitative research studies involving social and ethical inquiries, is vital to develop and advance new pharmacological and psychosocial interventions aimed at treating symptoms, modifying disease progression, and improving quality of life for persons with dementia as well as their family carers and supporters. However, while the awareness of dementia in the general population continues to rise, participation of people affected by dementia in research remains limited, and recruitment

remains a challenge. The reasons for this may be multifactorial, one of which is that health and care clinicians may find this form of conversation difficult to hold. Perhaps due to their own lack of knowledge and skills in understanding what the research is about to then be able to confidently answer any early questions and to then seek interest in a person's participation.

This paper describes the development of an on-line course aimed at increasing confidence in conversations about research to increase recruitment of with people living with dementia and their family carers and supporters to research studies. The module will be piloted in the body of Admiral Nurses (specialist dementia nurses who offer case management to families affected by dementia in the UK), evaluated and then rolled out to other health and care professional groups. The project has been undertaken in partnership between Join Dementia Research and Dementia UK, the charity that supports the development of Admiral Nurses. The on-line course consists of four modules that takes participants through four modules to include a background and rationale, the value to affected by dementia, aspects of research mindedness, through to scenarios that model various conversations. The on-line course is supported by a workbook to build on the participants understanding and can be used towards professional revalidation.

Policy - Dementia work force

POS2. Posters - Policy

POS2-11Supporting dementia support workers to adapt to their role within a primary care setting: what works, for whom and in what circumstances

Hannah Wheat[1], Hannah Wheat[1], Hannah Shafi[2], Tomasina Oh[1], Lauren Weston[1], Sarah Morgan-Trimmer[3], Basharat Hussain[4], Paul Clarkson[2], Richard Byng[1], Michael Clark[5]
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Case management, within primary care, is increasingly viewed (and evidenced) as the most impactful approach to post-diagnostic support for people living with dementia. Throughout the UK, dementia support workers (DSWs) have, to varying degrees, been given the role of case manager. While outcomes from DSW support are increasingly explored, little attention has been given to how best support DSWs to deliver personalised care. This is surprising as by attending to DSW support needs, their delivery of support can be enhanced and

workforce retention could be improved. To better understand DSW support needs, insights into what contextual factors (e.g. previous experience, work-placed culture, availability of community resources) can affect their adoption and adaption to the role in various settings are required. Such insights can be used to ensure that initial and ongoing opportunities for development and support are based on what needs arise in practice. The Dementia PersonAlised Care Team (D-PACT) study has used a realist approach to develop and (currently) evaluate a primary care based DSW role. A core focus within D-PACT programme theory on how various forms of support (e.g. supervision, peer support, support from general practice surgeries), in certain contexts, can help trigger the type of changes in DSWs (e.g. increased knowledge of how to navigate the system) that can generate positive changes in DSW behaviour and longer-term outcomes. Within the study, a range of longitudinal qualitative data (e.g. interviews, observations, reflection logs) has been collected from 8 DSWs and those who have provided support. The analysis will test, elaborate and refine programme theory statements relating to when, how and for whom various forms of DSW support worked. This presentation will share the results of this analysis and provide evidence-based guidance on how DSWs can be best supported to deliver personalised care in practice.

Policy - Dementia work force

POS2. Posters - Policy

POS2-12Confident conversations in dementia research in Scotland

Emma Law[1], Emma Law[2], Jacqueline Kerr[3]
[1]Neuroprogressive and Dementia Network, [2]Neuroprogressive and Dementia Research network, [3]Neuroprogressive and Dementia Research Network

My presentation will tell the story of the idea and subsequent delivery of the Confident Conversations in Dementia Research programme.
The Neuroprogressive and Dementia Network (NDN) in Scotland with the help and support of Alzheimer Scotland found that one of the ways to open up the conversation about research with potential participants is by teaching those people who have the best relationship with the person with dementia and their carer. In Scotland these are the link workers and dementia advisors employed by Alzheimer Scotland.
I will outline the support programme including the workbook which attendees can take away with them, videos from the NDN Partners in Research patient and public involvement group

talking about their experiences of research involvement, a postcard which acts as an aide memoire to the support, how to link to local researchers and links to current research findings. The overall outcome is to gain new knowledge about research and how to give people a toolkit of ideas to talk to people about how they could become involved.
I will show how this approach can be done in an informal, no questions barred atmosphere with group work, role play and lots of fun learning. I will present the findings from the 172 (to date) participants in our programme, who without exception at the end of the day, have expressed they felt more confident about approaching the subject of research.
I will outline our future plan to expand this to some of our health colleagues as well as devise a follow up plan. It is our core belief that the people best able to talk to someone about research are those with the best relationship with that person. Our programme aims to give people the confidence to have these conversations.

Policy - Dementia work force

POS2. Posters - Policy

POS2-13Building capacity in applied dementia research

Ruth Bartlett[1], Hannah Wheat[2], James Faraday[2], Sarah Smith[2], Tamara Backhouse[2], Esther Gerritzen[2], Megan Polden[2]
[1]University of Southampton, [2]

There have been increasing calls to strengthen research capacity to inform policy, improve care and support for people living with dementia, and develop innovative approaches to dementia. Governments around the world are urged to invest in the development of early career researchers so that knowledge of what works across the dementia landscape can advance and be shared with experts in the field, including people with dementia, family carers, and care professionals.
In this presentation, we report on a capacity-building scheme for post-doctoral researchers working in applied dementia research – that is, research aimed at finding solutions to the complex and diverse range of problems related to life with dementia. The scheme, known as DEM-COMM, supports the development of 58 early career researchers working in one of the 15 Applied Research Collaborations (ARCs) across England. Early career researchers from across the world are in England working on various innovative projects, from big data research to service evaluations and exploratory studies about end-of-life care. The scheme is funded by the National Institute for Health and Care Research and the Alzheimer's Society (UK). It aims to prepare a future cohort of researchers for the role of Chief

Investigator in applied dementia research, which is an important and specialised role that carries with it the expectation that peoples' lives will improve as a result of the work.
The DEM-COMM scheme launched in October 2022 and will finish March 2026. We have collected data about the cohort through surveys and have run capacity and community-building events, including a Winter School, webinars, and Special Interest Groups. Our focus in this talk is on the successes and challenges the cohort has experienced, including the wealth of opportunities for peer support and career development, and challenge of being part of a new national scheme that runs across different organisations

Policy - Campaigning for change

POS2. Posters - Policy

POS2-14France Alzheimer's first "MEMORUN"

Kevin Rabiant
France Alzheimer

In 2023, for World Alzheimer Month, France Alzheimer and related diseases organized a national campaign around 3 main events:

- Our first MEMORUN: a race in a famous park in Paris ;
- A "Village Alzheimer" on the race site ;
- A conference: "*Sport and brain: risks, prevention and benefits*". Sport is often associated with good health but there are still risky practices inherent to certain sports and talking about it is essential.

This first edition of Memorun had various objectives:

- Gather the general public, people living with dementia, their caregivers… around a sportive and festive event.
- Enhance a great mobilization around the fight against dementia and change the perception around the disease and people living with dementia.
- Raise awareness and promote risk reduction through physical activity.

The general public had the option to register for a run of 5km or 10km or a 5km walk. We also organized a race for children of 1km.

During the weekend, we registered more than 1700 runners, with our main sponsor being Marie-José Pérec, the famous French runner.

The Alzheimer Village, on the race site, was the occasion to:

- welcome runners and the general public;
- provide information about the disease, its risk factors and risk reduction;
- enable people living with dementia and their caregivers to participate in a friendly event and share their experience;
- for everyone to try adapted physical activities, surrounded by volunteers and professionals.

In September 2024, France Alzheimer will organize its second edition of the Memorun, with the renewed participation of Marie-José Pérec, who became one of our ambassador and is greatly involved by our side.

Policy - Campaigning for change

POS2. Posters - Policy

POS2-15In the middle instead of not there - With our campaign we aim to bring people with dementia and their loved ones back into the center of our society

Sarah Hoffmann
hoffmannsgarten GmbH

In our everyday lives, the gap between the 'healthy society' and the 'society of the sick' is widening. Especially people with dementia and their loved ones often retreat into isolation upon diagnosis, which is harmful to them - we don't want to accept this and therefore aim to contribute to a change and a societal shift in mindset. But to change an attitude, one must tackle tough challenges. We start with what matters most: we want to enable people with dementia and relatives to attend theater performances and other cultural events without hesitation, by encouraging theaters, event venues, cinemas, museums, etc., to explicitly open their doors to them. Because people with dementia and their loved ones naturally have the

same cultural needs as all of us.
What exactly do we do?
The campaign will be started in Berlin. First of all, we work with cultural institutions in Berlin, which we will encourage to open their doors to people with dementia and their relatives. We will produce short clips and podcasts to address possible fears of the institutions and to provide staff (e.g. gatekeepers, cloakroom attendants, etc.) with some information about the needs of people with dementia.
Also we are planning a big launch event in 2025 at which we want to make our initiative public
and known. Musicians will perform there who appeal to several generations. Before and through this event, we will launch a visible awareness-campaign to attract more and more dementia-
friendly organizations. The aim is to develop the initiative throughout Germany, and even across Europe, and to also be effective outside the cultural scene (gastronomy, sports…). Communicating this and creating suitable inclusive offers is the aim of our initiative "in the middle instead of being there.

Policy - Dementia work force

POS2. Posters - Policy

POS2-16Adding life to years: practice-based research for enhancing living well with dementia

Simone Bruin de[1], Gözde Duran[1], Anouk Jansen[1], Rens Brankaert[2], Muriel Van Doorn[2], Hans Hobbelen[3], Marlies Feenstra[3], on behalf of the PRO-DEM collaborative[4]
[1]Windesheim University of Applied Sciences, [2]Fontys University of Applied Sciences, [3]Hanze University of Applied Sciences, [4]

Traditionally, biomedical approaches have dominated understandings of dementia, seeking for causes and cures. Nowadays, there is space for a more psychosocial approach to dementia. This shift has also given rise to practiced-based research in the Netherlands, which concentrates on the lived experiences of people with dementia, their psychosocial needs, and enhancing dementia care and support practices. While this development has resulted in a growing number of interventions for people with dementia, their families, and health and social care professionals, it has also led to research fragmentation. In response, in 2023 a team of 23 Dutch professors from 13 different universities of applied sciences

conducting practice-based research, joined forces and established the PRO-DEM ('practice-based research for people with dementia') collaborative. PRO-DEM aims to promote living well for people with dementia by fostering interdisciplinary collaboration among researchers. Additionally, it seeks to build reciprocal relationships among stakeholders in practice-based research, education, and care practice. By doing so, we aim to better align the competencies of health and social care professionals with the needs of people with dementia and their families. Moreover, we aim to accelerate innovation in dementia care and support. During this presentation, we will provide three examples of how we work on strengthening of competencies of care professionals: 1. Cultural competences to improve access to health and social care for ethnic minorities; 2. Technological competences to support the utilization of warm technology in nursing homes and 3. Collaborative competences to strengthen interorganizational collaboration to innovate opportunities for learning and development of health and social care professionals. These examples support our belief of the importance of collaboration in PRO-DEM. Joint learning is crucial to enhance living well with dementia and supporting health and social care professionals in strengthening their competencies. Furthermore, sharing good practices prevents researchers from reinventing the wheel.

Policy - Dementia work force

POS2. Posters - Policy

POS2-17Evaluation findings and recommendations of the Dementia Care and Support Home Care Worker Education programme

Kate Brennan
National dementia Office

In Ireland Health care Assistants (Home support) provide the majority of home Care to people living with Dementia. One of the six priority action areas outlined in the Irish National Dementia Strategy is Training and Education.

Health and Social Care professionals and other staff working in the sector highlighted that they would like more training/education in dementia care. It was recommended in the Independent evaluation of the Irish National Dementia Strategy that health and social care staff should be dementia aware: those delivering care should receive dementia training appropriate to their role to provide understanding of the needs of Person living with Dementia and Carers.

In response to this priority the Dementia Care and Support Programme for Health Care Assistants was designed in partnership by the National Dementia Office (NDO), Health Service Executive (HSE), and Dublin City University (DCU), in collaboration with people with dementia and family carers. The aim of the programme is to develop skilled, reflective and self-aware health care support assistants to provide care to people living with dementia with humanity, empathy, and dignity.

The programme was awarded a Quality and Qualifications level 5 QQI in 2021 and was rolled out on a pilot basis in from 2021 to 2023. The NDO commissioned an independent process evaluation by University College Dublin in 2023 to capture impact and process of this training programme.

The Evaluation has

- Identified process issues to enable expansion and streamlining of the delivery of the Dementia Care and Support Programme.
- Provided evidence on the effectiveness and impact of the programme on (i) learners, (ii) managers and (iii) care recipients.
- Provide recommendations to assist with a national rollout of the programme.

Findings and recommendations from the evaluation will now be shared with delegates at the Alzheimer Europe Conference.

Policy - Dementia work force

POS2. Posters - Policy

POS2-18Transforming dementia care: a bio-psycho-social training model for residential facility professionals

Elisa Bruni, Elena Luppi, Aurora Ricci
University of Bologna

Background: The demographic change, characterized by the increase in the older population with specific care needs, requires a change in health policies and in the workforce training of formal carers. This implies the transition towards more holistic bio-psycho-social approaches. In response to this, the adoption of different approaches to dementia care and a re-evaluation of care staff training becomes imperative.

Aim: To promote a cultural change in care by developing a training model for professionals in residential facilities for frail older people.
Methods: The research design presents an exploratory study with sequential phases in a mixed-methods perspective. In the qualitative step, semi-structured interviews and focus groups were conducted with care home professionals to explore their experiences and perceptions about care, particularly in the midst of the pandemic. A questionnaire was then used to assess the training needs of 80 members of care facility staff. Based on the results, a training model has been developed for 54 facilities of the Local Health Agency of Bologna. The effectiveness of the model has been measured using a questionnaire (ex-ante and ex-post) and the projects developed by the participants during the on-the-job training.
Preliminary findings: The thematic content analysis explored the experiences, perceptions, and learning needs of professionals in relation to care, taking into account their experiences of the pandemic. To deepen the analysis and explore the content at a deeper and more latent level, additional themes were then brought to light thanks to a content analysis inspired by the Lifecomp Framework. The results of the questionnaire highlighted the need for professionals to update their skills in the appropriate use of restraint and non-pharmacological approaches as an integrated alternative in care.

Policy - Dementia work force

POS2. Posters - Policy

POS2-19Educational programme for nurses: leaders of best practices in dementia care in the Czech Republic

Iva Holmerová[1], Martina Nováková[2], Alzběta Bártová[3], Johana Křížová[4]
[1]Czech Alzheimer Society, [2]Charles University FHS CELLO, [3]Charles University, FHS and HTF, [4]Institut pro další vzdělávání pracovníků ve zdravotnictví

The Czech Republic has a population of 10 million, with 180,000 people living with dementia. Due to the aging population, the prevalence of dementia is expected to increase rapidly, nearly doubling by the middle of this century. People with dementia are becoming more common as patients in acute hospital departments, making up about 60% of patients in follow-up care hospitals and senior homes, and 80-90% of clients in long-term care facilities and special care homes.

The care needs of these individuals are determined not only by dementia but also by other social and health factors, including comorbidities. Qualified healthcare personnel, especially nurses, play a crucial role in caring for people with dementia and should lead best practices in dementia care. Our pilot study has shown that even a short education can improve care quality and reduce the burden on caregiving teams. However, there is currently no comprehensive educational programme to prepare nurses for the important leadership role. An educational programme for nurses is therefore extremely necessary.

To address this need, the Institute for Further Education of Healthcare Workers in Prague (IPVZ), in collaboration with Charles University FHS CELLO, and other experts, is developing and implementing an educational programme. This will include 20 hours of online theoretical education, 20 hours of in-person teaching, and 20 hours of practical, experiential learning. It will also feature excerpts from a recent film documenting the life of a woman with dementia and the experiences of her caregiving family ("Dance Matilda").

The curriculum of this educational programme, along with the initial experiences and results from the pilot study on caregiver burden, will be presented in detail on the poster.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-01In Styria there is a day center for disabled people with dementia. And I would like to be a voice for the fact that disability and dementia are also a big issue

Marianne Wilfling
LebensGroß GmbH

We are an organisation based in Styria, which has decided to support impaired people in all situations of life. Due the fact that in the work with impaired people, on the one hand, there is medical support and, on the other hand, now the generation after the hitler regime is appoaching the senio age, we also have in our day center for impaired people, a focus on dementia.
As a very busy professional, i would like to draw a bow between dementia in the conventional senior age and how we live our work and meet our participants with dementia. Based on our day center, working with impaired seniors is often allready challenging, but if the "assumption" or diagnosis of dementia is added, the challenges increase massively.

We accompnay 30 participants, of which there are 5 diagnosed forms of dementia, our dark figure is much higher. Thats why i decided to furhter educate myself to become a dementia manager. In the course of this i offer training for colleagues and work intensively with the impaired people and dementia. In my daily work it is very difficult to make diagnoses, becuase there are hardly enough suitable doctors, etc. who wants to deal with my clientele. For me the combination of Down Syndrome and dementia is on the one hand a very exciting work and on the other hand a very emotional challenge, because of the rapid progression. With my abstract i want to comminicate that impaired people also experience dementia and thus also show this picture to the population.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-02Moments of resonance: creating socio-material connectivity through museum visits for people with dementia and their relatives

Julie Bønnelycke, Pernille Kjærgaard Christiansen, Julie Bønnelycke, Lars Pynt, Hanne Peoples
UCL Erhvervsakademi og Professionshøjskole

In a qualitative study on the experiences and interactions of people with dementia and their relatives during visits to a Danish Cold War Museum, we study how connectivity occurs through moments of resonance and engagement within socio-material assemblages at the museum and in the home. Using participant observations and qualitative interviews, and drawing from material feminism and socio-material approaches, we identify moments of resonance as pivotal for creating connectivity between people with dementia and their partners or relatives.
The term ‘resonance’ stems from latin resonantia, meaning echo, re-sounding. Echoes traverse time and space, exchanging variations of an original sound, re-activating it with each pass between actors. Resonance can be understood as attunement, as tuning into each other, becoming-with each other.
Drawing from particularly poignant moments and events during our fieldwork, we conceptualise moments of resonance as situations where memories are re-awakened; where echoes of past emerge and are persist through the exchanges between actors. These moments of resonance are activated by the coming-together of human and non-human actors and activities within site-specific situations and constellations. We therefore interpret these moments as instances of socio-material-spatio-temporal connections in the museal meetings

between people and objects, events, memories, personal narratives, and past and present selves. Resonance creates situated connection that can be sustained and renewed despite changes in the people and actors present. It is thus not dependent on the memory or reminiscence of a singular person but is distributed and continually transformed and renewed through exchange.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-03Impact of informal caring for people with mild cognitive impairment: a cross-sectional study in Spain

Elena Garcia Arcelay[1], Sagrario Manzano[2], Mariló Almagro[3], Mircea Balasa[4], Gerard Piñol-Ripoll[5], Merce Boada[6], Lamberto Landete[7], Eloisa Navarro[2], Inmaculada Abellán[8], Angel Berbel[9], Beatriz Espejo[10], Miquel Baquero[11], Juan Marín[12], Emilio Franco[13], Jorge Mauriño[14], Pascual Sanchez-Juan[15]

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Background: Despite the crucial role played by informal caregivers, their experiences and the stress they endure are frequently overlooked. The aim of this study was to assess the impact of informal caregiving for individuals with mild cognitive impairment (MCI) in Spain.
Methods: We conducted a non-interventional, cross-sectional study at 19 dementia clinics in collaboration with the Spanish Confederation of Alzheimer's Disease (CEAFA). Individuals providing informal care for people with a diagnosis of MCI (National Institute on Aging and the Alzheimer's Association clinical criteria) and a Global Deterioration Scale score of 3 were included.
The Zarit Burden Index (ZBI-22) was used to assess caregiver stress. A multivariate logistic regression analysis was conducted to determine the association between participants' characteristics and the impact of caregiving.
Results: A total of 196 caregivers were included. Mean age (SD) was 63.5 (13.1) years, 62.8% were female. 68.4% were spouses of individuals with a mean age of 72.9 (SD 7.0) years and a Mini-Mental State Examination score of 26.0 (IQR 23.0-27.0). A total of 41.8% (n=82) had anxiety and 18.9% (n=37) depressive symptoms. The mean ZBI-22 score was 22.3 (13.6). Overall, 59.7% (n=117) of participants reported experiencing caregiver stress (ZBI-22 score ≥17). These individuals exhibited higher levels of anxiety and depressive symptoms, a more pronounced perception of stigma and hopelessness, increased avoidant coping strategies, lower resilience, poorer caregiver-individual relationships, and perceived inadequate social support compared to their counterparts.
Caregiver stress was associated with anxiety (p=0.017), stigma (p=0.007), emotional distress caused by neuropsychiatric symptoms (p=0.0001), and the need for a broader social support network (p=0.0001) in the multivariate analysis.
Conclusions: Informal caregivers of people with MCI in Spain experience significant stress. The identification of factors contributing to their stress can assist healthcare professionals in implementing specific early interventions to address these challenges.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-05Family-centred Reminiscence: Insights from a collaborative action research study

Connor McDonald[1], Debbie Tolson[2], Bryan Mitchell[2], Anne Marie Craig[2]
[1], [2]University of the West of Scotland

For families of relatives living with dementia in nursing homes, maintaining familial connections is paramount. This talk will explore discoveries from a collaborative action research study exploring the practicalities and usefulness of family centred reminiscence within family visits. Six family members and staff from one Scottish nursing home are collaboratively building practical understanding and insight into positive approaches to family led reminiscence. The theory guided study draws upon the Senses Framework and Relationship-Centred dementia care.
Individual family member interviews were completed to sensitise the researcher to the caring situation and visiting experiences. Few had direct experience of reminiscence and described a range of visiting experiences from good to upsetting. A project video was filmed to introduce participants into how reminiscence can be used with people with advanced dementia including tips on communication approaches. Subsequent group activities were designed to develop a sense of team, mutual understanding of visit challenges, and their current approaches that resonated with reminiscence. The relationship building aspects promoted peer to peer learning and a shared sense of the project's importance to them, their relative, and wider family. The second action cycle comprised a series of four group workshops interspersed with reminiscence in action with follow-up phone interviews. Methods will be elaborated, reporting on the use of gentle approaches to developing an understanding of dementia related changes over time, how to select reminiscence topics and introduce reminiscence within their visits. A modified emotional touchpoint approach was used to compare how families felt at various points of the visit experience before and after trying reminiscence with their relatives. Results will be explored to hear the voices of participants to reveal their developing confidence in using planned reminiscence activities within visits, which formed the basis for a co-developed resource to be used by other families.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-07"Zum Augenblick" - the dementia restaurant

Günter Hymer, Susanne Bayer, Karl Galeitner, Tamara Nemeth, Karin Eder
Häuser zum Leben

Background: Relatives of a person with dementia often have reservations about eating out in public with their loved ones. This happens out of fear that the person affected might behave improperly or conspicuously, putting them in an uncomfortable situation.
For this reason, family parties and celebrations with people with dementia often take place in private.
This exclusion from everyday life is clearly perceived by the “Häuser zum Leben”.
However, as the company's goal is inclusion and participation, it is working to ensure that people with dementia do not disappear from the public eye, but are recognized as part of everyday life.
It is not the patients who have to adapt to society, but we have to create structures to give them the opportunity to be an equal part of society. In the long term, it should be just as normal to sit next to people with dementia in restaurants as it is to sit next to wheelchair users, blind or deaf people, for example.
Goal: The people with dementia take centre stage! A system is created around them that gives them the opportunity to make their own decisions and cope independently in the restaurant situation. Those affected are accompanied by their relatives, but the organisation of the event is primarily adapted to the capabilities of those with dementia. In the best case scenario, those affected and their relatives gain enough self-confidence to go out to eat in public restaurants.
The “Häuser zum Leben” advocate equal rights and respectful treatment of people with dementia in everyday life, which can lead to a positive socio-political change.
Methods:

- Invitations and menus in simple language
- Room and table design clearly organized and structured
- Food selection using display plates
- Specially trained service staff
- Information material for relatives as support

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-08Online peer support for people with dementia: a scoping review

Esther Loseto-Gerritzen[1], Catherine Talbot[2], Orii McDermott[1], Martin Orrell[1], Neil Coulson[1]
[1]University of Nottingham, [2]Bournemouth University

Background: People with dementia engage with a variety of online platforms for peer support, for example discussion forums, and social networking and videoconferencing sites. Our previous work involving people with Young Onset Dementia shows that online peer support can be someone's lifeline post-diagnosis. Online platforms can offer a variety of benefits, such as overcoming geographical barriers and different modes of communication. However, our research also showed that many people are unaware that online peer support exists, what it entails, and where to find more information. A scoping review can help creating an overview of online peer support opportunities for people with dementia.
Aims: This review aims to explore what online peer support opportunities are available for people with dementia and what the characteristics are.
Methods: This review follows the JBI methodology for scoping reviews and the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR). Four data sources are used: (1) scholarly and grey literature databases, (2) Google search engine, (3) social media and websites of UK-based and international dementia organisations, and (4) consultations with people with dementia and professionals. The screening and study selection will be conducted by two independent reviewers. Reference lists will be hand-searched, and people with dementia and professionals will be consulted to ensure that any online peer support groups that were not identified through the searches are included.
Anticipated results: We are currently searching, screening and selecting the results. The findings will provide insights into what online peer support opportunities exist and help determining whether any gaps exist in availability and accessibility of online peer support for people with dementia. We will write a lay summary report and disseminate this among people with dementia, professionals, and dementia organisations, to help further improve availability and accessibility of online peer support groups.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-09What should I do now? Exploring times without care for people with dementia in elderly care

Ulrike Lindwedel[1], Peter König[2], Thomas Beer[3], Helma M. Bleses[4], Matthias Kliegel[5]
[1]Furtwangen University, [2]Furtwangen University / Care & Technology Lab, [3]Eastern Switzerland University of Applied Sciences, [4]Hochschule Fulda, [5]University Genf

As part of the binational research project FreiZeit, a variety of methods are being used to investigate what people with dementia do when they are not doing anything. Using observations, focused videography, situational interviews with people with dementia and interviews with their formal and informal caregivers, these times in which people with dementia are not involved in predetermined activities and care times are considered. The sample included 30 people with dementia in different stages of dementia in institutional and home-based long-term care settings in Switzerland and Germany. For the first time, "free time typologies" were developed on the basis of ethnographic methods.
The findings indicate that people with dementia evoke a wide variety of activities and behaviors during care-free periods. Preliminary 11 different "free-time types" were identified. These are people who (a) seek activity, (b) work, (c) actively occupy themselves, (d) seek attachment, (e) relax, (f) stage themselves, (g) seek contact, (h) seek orientation, (i) are on the move and (j) withdraw (k) the caring. These types were further described using a matrix containing various dimensions and their characteristics, such as "emotionality" or "physical activity". The analyses showed that people move fluidly back and forth between different types and change activities. Accordingly, people can also be assigned to several types.
The typology provides an initial insight into how people with dementia experience care-free periods. These findings provide an important basis on which person-centered measures can be developed or derived. In a future step, a person with dementia can be offered appropriate services according to their type.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-10Exploring the decision-making around behavior affecting food and fluid intake in persons with dementia: a multiple case study

Eline van Buuren[1], Jenny van der Steen[2], Christian Bakker[3], Raymond Koopmans[4], Marieke Perry[5]
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Background: Persons with dementia can experience behavior complicating the intake of food and fluids in the course of the disease, resulting in a critical status of nutrition and hydration. Healthcare professionals and relatives may face ethical dilemmas that complicate decision making.
Objectives: This study aimed to explore the process of decision-making and ethical dilemmas regarding behaviors that adversely affect the intake of food and fluids in persons with dementia living in long-term care facilities.
Methods: We used a qualitative multiple case study approach. We interviewed family members and healthcare professionals using a semi-structured interview guide. We identified cases of younger and older persons with dementia in whom behavior affecting food and fluid intake was observed. Four cases were studied, comprising thirteen interviews with four family members and nine healthcare professionals. Interviews were transcribed verbatim and thematically analyzed.
Results: Three themes were identified: 1) 'balancing resident autonomy versus nutrient sufficiency', i.e. navigating between weight preservation without coercion while considering the residents' quality of life and (presumed) wishes; 2) 'searching for a personalized approach regarding eating and drinking', i.e. the care team recognizes resident preferences and provides a person-centered intervention, ensuring positive eating experiences and assistance during mealtimes, taking staff shortage into account; and 3) 'understanding the person with dementia and their behavioral challenges with food and fluid intake', i.e. the need to interpret the expressions of behavior and underlying causes, considering the meaning of eating and drinking for the person.
Conclusion: This study underscores the ongoing need for a person-centered approach to manage behaviors that affect food and fluid intake. Those involved in care should achieve an appropriate balance between autonomy and quality of life and adequate nutritional intake. The perspectives from this study can aid multidisciplinary teams in nursing homes in navigating complex decision-making.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-11Social frailty and social isolation in people living with dementia: a simultaneous concept analysis

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Background: Early management of risk factors related to social health can alter the progression of dementia. Social frailty and social isolation are described as social health markers. However, the similarities and differences between these two concepts are unclear due to overlapping definitions. A clear understanding of these concepts is needed so that they can be interpreted correctly.
Aim: This simultaneous concept analysis aims to examine the literature for definitions of social frailty and social isolation and explore similarities and differences between these concepts in the context of dementia.
Method: The nine-step simultaneous concept analysis method by Haase et al. was employed. Literature from six databases, Ovid Medline, CINAHL, PsycINFO, Scopus, Embase and Cochrane Library, were reviewed. Original research and review papers that report on the definitions of social frailty or social isolation, published in English, were included. The data analysis is currently ongoing, for which Braun and Clarke's six-phase thematic analysis is being followed. This simultaneous concept analysis was registered on the Open Science Framework.
Preliminary results: There are overlaps between the attributes of social frailty and social isolation, regarding being alone, having limited or reduced social activities, engagements, or interactions. The specific attributes of social frailty include financial difficulties while social isolation is distinctly marked by a lack of social networks.
Discussion: It is important to provide a clear understanding of social frailty and social isolation in the context of dementia. By clarifying the similarities and differences between these two concepts, our findings will help the development of interventions to prevent social frailty and social isolation in people with dementia. This will help address the specific needs of individuals living with dementia; thereby enhancing care delivery and improving their health outcomes.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-12Supporting communication in advanced dementia: insights from familial and professional caregivers

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Background: Advanced Dementia (AD) is characterised by severe cognitive and language impairment. This can impact person centred care as it presents profound challenges for caregivers in appropriately responding to the care needs and wants of the person with dementia. Advanced dementia is often considered a disorder of consciousness whereby the person has a profound impairment in arousal (i.e., the state of consciousness) and awareness of the self and the environment. As the number of assessments in establishing a behavioural repertoire of non-verbal communication in disorders of consciousness post brain injury builds, this study aims to explore their utility in understanding a person's awareness level and preferences for non-verbal communication for the person living with advanced dementia and their caregivers.
Method: Informed by a qualitative descriptive approach, this study utilised purposive and snowball sampling to recruit both familial and professional caregivers of people with advanced dementia. Focus groups are being conducted with familial caregivers and professional caregivers in Ireland. The data will be analysed using thematic analysis (Braun & Clark, 2019).
Results: Data collection is ongoing and will cease in June 2024.
Conclusion: It is envisaged that this study will increase knowledge and awareness of non-verbal communication in advanced dementia, as well as provide an initial insight into the utility of consciousness assessments for this population.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-13Stopping driving: what are the recommendations for people living with dementia and their families?

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The Fondation Médéric Alzheimer produced recommendations in 2024 for people with dementia and their families, to help them through the complex process of giving up driving. An initial version was drawn up based on an international review of the literature and the results of surveys carried out by the Foundation. This document was completed and improved by people with dementia who had recently stopped driving (focus group) and also by caregivers of people who had stopped driving (other focus group).
Many people think that driving remains a simple and automatic process. It is important to remember the complexity of driving: understanding and reacting appropriately to everything

you see and/or hear (traffic lights, road signs), taking appropriate measures (braking, changing lanes) to avoid obstacles, maintaining your attention and concentration, anticipating the actions of other drivers, etc. The aim is then to explain how cognitive disorders will make it difficult to carry out these different tasks, usually simultaneously. Some signs are precursors to potentially dangerous driving, while others are warning signs that driving should be stopped.
Talking about stopping driving is a delicate subject. There are so many reasons to postpone this conversation. The recommendations provide a starting point for the conversation. It is also important to remember that everyone will have to stop driving at some point in their lives, to recognise that it is difficult to give up driving but that it is still possible, and to put forward other means of transport: carpooling with a relative, for example. If the conversation doesn't go well, it's best to wait and continue the conversation another time. In addition, it's a good idea to think ahead: who's going to drive and ensure mobility within the family afterwards? The role of the general practitioner and the driving licence doctor has also been clarified.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-14The perceptions and needs of dementia informal caregivers in Portugal: insights from the "Living with Dementia" project

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Background: Dementia significantly affects not only individuals diagnosed but also their informal caregivers. The Nova Center for Global Health at NOVA-IMS, in partnership with the Alzheimer Portugal Association, undertook an in-depth study to examine the various facets of daily life that impact informal caregivers of people with dementia in Portugal. Gaining insight into these effects is vital for creating targeted interventions that effectively address caregivers' needs in health and social education (literacy + citizenship).
Methods: The research involved a carefully designed survey based on 14 key areas identified by informal caregivers and validated by dementia specialists. This was complemented by in-depth interviews with experts in neurology, psychology, and social work, as well as with caregivers. The comprehensive survey was then distributed to

members of the Alzheimer Portugal Association and other volunteers, resulting in 305 valid responses. The study was conducted from April 2023 to April 2024.
Results: Initial results indicate that caregivers face significant emotional, physical, and financial challenges, highlighting the varied needs across key areas of their lives. The research identifies specific areas where support is lacking, offering a robust basis for the development of more effective support systems.
Conclusions: The "Living with Dementia" project sheds light on the intricate challenges experienced by informal caregivers. It advocates for innovative and practical solutions to reduce their burdens and enhance their quality of life. By addressing the specific needs uncovered by this study, policymakers and support organizations can better tailor their interventions to support those who are essential in the care of individuals with dementia.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-15Behavioral characteristics of nightly agitation in people with dementia living at home and in nursing homes: a scoping review

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KU Leuven

Behavioral symptoms in dementia are consistently shown to be highly burdensome to caregivers. Nightly agitation is a commonly reported symptom in people with dementia (PwD) and encompasses a wide range of disturbing behaviors during the night. It is especially burdensome to informal caregivers as it interrupts their sleeping routine and impacts their and PwD's functioning during the day, while in the nursing homes, it can be disturbing to other residents. Currently, there is no definition and overview of behaviors that would fall under the term nightly agitation, making it difficult for caregivers and clinicians to accurately recognize nightly agitation in time and develop appropriate interventions. The aim of this scoping review was to explore the range of disturbing behaviors which are reported during the night in PwD living in their homes and PwD residing in nursing homes and possibly compare the two populations. This review follows PRISMA Guidelines for Scoping Reviews. Medline, Web of Science, ProQuest Psychology, CINAHL and OSF for preprints were searched for dementia and sleep disturbances – January 8, 2024. The following inclusion criteria were used: 1) empirical journal articles, research reports or preprints, 2) population with dementia, 3) sleep disturbances or nightly agitation as a studied phenomenon, and 4) examination from the observable/behavioral perspective. The screening

process was performed by two independent researchers in two phases. First, abstracts and titles were screened for the above-mentioned inclusion criteria, and second, full texts were screened against the same criteria with the additional criterion of at least one reported behavioral characteristic of nightly agitation. In total, 13 studies were included in the analysis. The results of the study will be presented and discussed during the conference presentation.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-16Lifestyle and environment to improve quality of life in the dementia care triad: a focus group study on quality of life

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On behalf of the SPREAD+ consortium
Background: Lifestyle and environmental factors play a vital role in maintaining and enhancing quality of life in dementia. Neglecting these poses risks for the care triad. Informal caregivers often prioritize the person with dementia over their own health and well-being, putting them at risk for chronic health conditions and profound exhaustion. Stress and long hours of care also present challenges for professionals to engage in healthy lifestyle behaviors. Professionals face pressure from heavy workloads, which will intensify with the aging of the population, compounded by a decline in the workforce. Understanding the influence of these factors on quality of life of the care triad is crucial for improving support.
Objectives: This study aims to explore which lifestyle and environmental factors contribute to quality of life of people with dementia, their families and care professionals. We further aim to identify potential facilitators and barriers to improving these factors.
Methods: We are conducting a qualitative study using focus group with the care triad. We aim to include 45 participants. Each group has 4-8 participants. Each part of the triad has its own groups, to not influence the results and include tailored questions. Participants received

a 'sensitizing task' to prepare them for the focus group. Two researchers independently assess data saturation.
Results: Focus groups are ongoing but final results are presented at the conference. Preliminary results suggest that people with dementia have a heightened need for emotional support, and physical and cognitive exercise. Informal caregivers prioritize activities to recharge, like social interactions, physical exercise or relaxation activities.
Conclusion: This study aims to contribute to the needs-driven psychosocial support to maintain or improve the quality of life for the care triad. Insight into challenges and needs is necessary for timely, effective and sustainable implementation.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-18National Dementia Carers Action Network - For Carers, By Carers

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[1]Alzheimer Scotland, [2]National Dementia Carers Action Network

The National Dementia Carers Action Network (NDCAN) is a member-led national active voice group of carers, and former carers of people with dementia. The campaigning Group exists to make the voices of dementia carers heard, raising awareness of the issues impacting on carers and influencing policy and practice at all levels.
NDCAN members previously participated in a conference on building resilience amongst family carers. They became interested in helping other dementia carers to be more resilient by sharing their knowledge and experiences of what has helped and worked for them. Through a suite of 'For Carers, by Carers' booklets, they shared experiences of what had helped carers in Scotland to get through the day and cope with adversity. Offering words of encouragement, tools and tips, the booklets were not a professional advice guide but what had worked for NDCAN members and the carers they heard from.
This year NDCAN members refreshed the resources, to ensure they remain current and effective. Recognising digital developments they've highlighted that technology and apps can help people to live well with dementia and provide peace of mind for carers; they've referenced current guidance and support; and they've reflected on advances in dementia care and practice.
Each leaflet now stands on its own, sharing information specific to where a carer is on their

dementia journey as well as providing general top tips and key information. The leaflets cover:

- Going for a diagnosis
- Helping someone with dementia to live well
- Working with professionals and services
- When problems arise
- Going into hospital
- Moving into a care home
- Looking after yourself
- Advanced dementia
- Grief and loss

'For Carers, By Carers' is carers speaking to and supporting other carers.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-19The significance of a dementia diagnosis from the perspective of the family caregiver

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Objective: With the anticipated increase in dementia prevalence over the coming decade, understanding the experience of receiving a dementia diagnosis remains limited. Such comprehension holds significant relevance for individuals diagnosed, their families, and healthcare providers. This study aims to shed light on the implications of receiving a diagnosis from the family caregivers' perspective by exploring their experiences of living close to people with cognitive impairment compatible with a dementia disease, some of them diagnosed with dementia and some neither assessed nor diagnosed.
Method: A qualitative descriptive design was used with individual interviews as the method for data collection. Participants were recruited based on the cognitive performance of their next of kin. The cognitive functioning was assessed with the Montreal Cognitive Assessment Scale (MoCA) and age-adjusted scores falling below the following specified thresholds: 70-79 years<22; 80-89 years<21; 90+ years<20 were included. The sample

consisted of 8 participants, comprising relatives of 5 individuals with confirmed dementia diagnoses and 3 undiagnosed. Transcribed interviews underwent meticulous qualitative content analysis, employing a systematic four-step process to discern codes, categories, and the overarching theme.
Results: Four main categories emerged from the interviews: (1) Initiatives taken for assessment of cognitive impairment; (2) Experienced need for assessment of those without a diagnosis; (3) The impact of a diagnosis on the knowledge and utilization of health and social services; (4) Received support and follow-up for family caregivers.
Our preliminary findings indicate that the use of services depends on the extent of available assistance from family and close relations, as well as the need for independence and self-sufficiency. Awareness of the services was significantly higher among family caregivers of individuals diagnosed with dementia compared to those of individuals without a dementia diagnosis.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-20Inter-rater reliability in Swiss community dementia nursing assessments: the example of the Integrated Palliative Care Outcome Scale for people with dementia (IPOS-Dem)

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Background: Proxy-completed assessment and outcome measures are important to support person-centred care of people with dementia. However, assessors are often concerned about the consistency of their measurements due to their proxy nature. The Integrated Palliative Care Outcome Scale for People with Dementia (IPOS-Dem) is a holistic measure for community/district nurses. We aimed to determine its inter-rater reliability.
Methods: A cross-sectional study, where two community/district nurses caring for a person

with dementia independently completed IPOS-Dem. Prior IPOS-Dem training was given. Inter-rater reliability was assessed via intraclass correlation coefficients (ICCs) in addition to prevalence and bias-adjusted kappa. Interpretation followed guidelines by Landis & Koch. Results: 118 nurses with a tertiary/diploma degree or nursing assistants independently completed IPOS-Dem for 146 people with dementia (mean age: 84 years, 95 women, 64 Australia-modified Karnofsky Performance Status ≤50%). Eighteen of 27 IPOS-Dem items showed good to very good inter-rater reliability (>0.60). The items Poor appetite, Nausea, Vomiting, Sore or dry mouth, and Problems with teeth/dentures demonstrated moderate to low moderate reliability. Family anxiety, Lost interest, No positive interactions, and Practical problems elicited fair reliability (ICCs = 0.31-0.39). Findings suggest that nurse-nurse pairs who had been caring for the person with dementia longer achieved higher concordance.
Conclusion: Most IPOS-Dem items showed good reliability, although several physical, social, and family symptoms and aspects are more challenging for nurses to assess reliably. Inter-rater reliability is strengthened when assessors know the person well. For a person-centred approach, training needs focus on eliciting information from the family and peers.

Living with dementia - Relationships and sexuality

POS3. Posters - Living with dementia

POS3-21Maintaining couplehood in the face of dementia: a qualitative evidence synthesis

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Background & Objectives: In both partners within a couple affected by dementia, the quality of their personal relationship is linked to the level of well-being. The body of research on how those couples experience the change in the relationship dynamics in the face of dementia, and what their needs in this context are, has been growing, bringing about the

need in synthesizing the accumulated knowledge. Importantly, the primary studies on relational needs seem to be dominated by the views and perceptions of caregivers. Therefore, we aim to synthesize evidence on the needs that people living with dementia (PLwD) and their partners have when it comes to maintaining couplehood, and to ensure that the voices of PLwD are well represented.
Methods: A qualitative evidence synthesis (QES) of available literature across four databases (PubMed, CINAHL, PsycINFO, Web of Science) will be conducted. ASReview – an artificial intelligence tool for accelerating the screening process in systematic reviews – is used, with the measures required for ensuring the quality of screening undertaken. Findings from the literature will be aggregated by making use of thematic synthesis. Next, those findings will be triangulated with the insights from the semi-structured interviews with PLwD. Visual prompts will be used to stimulate the engagement of PLwD in the conversation.
Status and expected results: Currently, the title and abstract screening stage is in progress. A synthesis of literature findings is expected to be finished by August, and the pilot of the interviews is planned for September 2024. During the conference we are planning to share the QES findings combined with the reflections and adaptations to the methodology for conducting the semi-structured interviews with PLwD.

Living with dementia - People living with dementia

POS3. Posters - Living with dementia

POS3-22Religion and the everyday citizenship of people with dementia in Nigeria: a qualitative study

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Background: There is a general lack of cultural diversity in dementia research. Research on the lived experience of dementia is burgeoning across the social and health sciences. Yet, very little is still known about the experience of dementia for many tribes and ethno-religious groups, as most studies are conducted in Western countries.
Objective: We aim to advance the understanding of the role of faith and prayer in the lives of people with dementia in Nigeria through a lens of everyday citizenship.
Method: Interviews were conducted with 17 older people with dementia in a low-income, Yoruba-speaking community in Southwestern Nigeria. After transcription, the data were analysed thematically.

Results: The major theme identified in participants' accounts was that prayer served as a space for active and agentic participation. This theme was further elaborated upon through four sub-themes: (1) agency in routine and daily prayer, (2) cognitive (re)framing through prayer, (3) prayer as a vehicle for active social interaction and support, and (4) prayer as work and transaction.
Conclusion: Participants described religious practices, such as faith in God and individual and communal prayer, as important to their acceptance of the situations, their feelings of hope in everyday lives, and their connection and contributions to the community. Our analysis also shows the centrality of relationality in the everyday experiences of people with dementia.
Contribution: This article contributes to advancing the understanding of the socially orientated everyday experience of dementia, drawing on narratives of everyday religious practices from people with dementia themselves. It contributes to a small body of literature on the social aspect and everyday experiences of living with dementia in Africa and stands out as the first of its kind study in Nigeria.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-24If you're just a little bit open, then you're part of the community – perspectives from elderly citizens living in a rural environment

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Introduction: Europe's population is growing older, with an estimate of almost 10.000 people living with dementia. In Denmark, healthcare services are funded by general taxes and the demographic development may thus pose a particular challenge for the economies of municipalities in rural areas, as they often have a relatively larger share of citizens with dementia. The local community thus plays a significant role in promoting healthy lives for people with dementia in rural areas.
Aim: To explore the perception of a meaningful home/local environment among elderly citizens, including people with dementia, residing in a rural setting.
Methods: A qualitative study, where data was generated at two public citizens meetings, a focus group interview, and a qualitative interview, with a total of 79 participants. The meetings were planned in close collaboration with relevant stakeholders.
Results: The analysis resulted in four categories reflecting essential factors: 1) To be able to

take care of oneself, 2) A good home – both physically, mentally, and inside and outside, 3) Meaningful activities and relationships, and 4) Infrastructure, transportation, and shopping Applied significance: The study underscores both the strengths and challenges faced by rural communities. One notable strength is the pivotal role played by civil society in ensuring a meaningful everyday life for elderly citizens, including people with dementia. Many participants engaged as formal and informal volunteers, making significant contributions to fostering an active local community. However, the participants also expressed a significant challenge: the lack of infrastructure, which negatively impacted people's autonomy, daily activities, and meaningful relationships.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-25What is known about fire risk and safety for people living with dementia at home?

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Introduction: Most people living with dementia prefer to continue living at home. However, as dementia progresses, people may become more susceptible to risk. This includes misuse of appliances and cooking accidents that can lead to fire. This is a common concern cited by people living with dementia, family carers, and healthcare professionals, but research in this area is lacking.
Methods: We conducted a narrative review of existing knowledge around fire risk and safety for people living with dementia at home. We contacted all 43 English fire services to explore what information they hold about fire incidents involving people living with dementia. We also searched scientific databases for peer reviewed literature, and Google and English Fire Service websites for grey literature to identify initiatives, interventions, and guidance around fire safety for people living with dementia.
Findings: Fire services in England do not record dementia status routinely and for those that do, methodological issues mean that available data is unlikely to be accurate. All fire services offer ‘Home Fire Safety Visits’, designed to help those vulnerable to fire identify and reduce risk at home however, very few specify that people living with dementia are eligible. Some fire services have produced fire safety guidance for people living with dementia, as have two UK dementia charities. Peer reviewed literature focussed on Assistive Technology and highlighted that technologies such as stove shut-off devices were difficult

for people living with dementia to integrate into everyday life and caused additional problems and risks.
Conclusions: We will conclude with suggestions for fire safety policy, practice, and future research. For example, we suggest that there is scope for standardised dementia fire safety guidance and awareness training to be developed and rolled out nationally to all fire services, with potential for similar development in other countries.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-26The role of the neighbourhood built environment: learning from the Dementia-inclusive Streets and Community Access, Participation, and Engagement (DemSCAPE) study

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[1]UBC, [2]

The neighbourhood is widely regarded as a setting that affords functional, social and psychological support and opportunities to maintain community-based activities and social participation for people living with dementia (PLWD). The "Dementia-inclusive Spaces for Community Access, Participation, and Engagement (DemSCAPE)" study aims to identify spatial and temporal patterns in activities undertaken outside home by people living with dementia, and ways in which the neighbourhood built environment affects their outdoor mobility and social participation. A series of sit-down and video and photo documented walk-along interviews were conducted with 32 participants who are living with (mild to moderate) dementia or mild cognitive impairment in the Metro Vancouver and Prince George regions of British Columbia, Canada. Findings shed light on how people living with dementia understand and navigate the neighbourhood environment, and features that prompt recall of routes, places, and events, and support orientation and wayfinding. Findings also underscore the importance of participants' awareness of barriers and obstacles in their neighbourhood, and how they cope with challenges and demands encountered while walking outside. The study offers planners and designers awareness and insights into the lived experience of navigating the neighbourhood environment with the condition of dementia and guidance on adopting a dementia-friendly and inclusive approach in policy and practice. To help municipalities achieve their vision of dementia-inclusive streets and outdoor spaces,

evidence-based Knowledge Mobilization (KM) resources were produced to create education and training tools for municipal planners, as well as members of community-based organizations.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-27How older people living with dementia experience the inclusiveness and friendliness of their city: development of a validated questionnaire

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The World Health Organization (WHO) engages cities and communities all over the world in becoming age-friendly. Expanding on this agenda, the WHO launched a new programme for dementia-inclusive and dementia-friendly cities and communities in 2021. An extended model was presented, with safety and carer support as new domains of action, supplementing the existing domains of age-friendliness. In order to move towards a dementia-inclusive society, the WHO provides a toolkit for dementia-friendly initiatives. To date, validated instruments for a baseline assessment are lacking. This is a great brake on moving the dementia-friendly agenda forward. Therefore, there is a need for assessing the dementia-friendliness of cities and communities by means of a transparently constructed and validated tool which measures the construct as a whole. The aim of this study is to develop a questionnaire measuring dementia-friendliness, providing full transparency and reproducibility. The development and validation of a new questionnaire follows the criteria of the COnsensus-based Standards for selection of health Measurement INstruments (COSMIN). Four phases are followed: (1) development of the conceptual model, themes and items; (2) initial (qualitative) validation; (3) psychometric validation, and (4) translating the instrument using the forward-backward translation method. This rigorous process of development and validation is expected to result in a valid, psychometrically sound, comprehensive questionnaire, building on experiences of the development of the Age-Friendly Cities and Communities' Questionnaire (AFCCQ). The novel questionnaire can be used to measure older people's experiences regarding the domains of the WHO Age-

Friendly Cities and Dementia-Inclusive Society's models. The questionnaire allows practitioners and researchers to capture the dementia-inclusiveness of a city or community in a numerical fashion, which helps monitor the dementia-inclusiveness and the potential impact of policies or social programmes. The dementia-inclusive questionnaire is created in Dutch and translated into British-English.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-28Narrative spaces: facilitating ongoing dialogues between people with dementia and their living environments

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This research delves into participatory design processes tailored for adults with dementia, adopting a dialogic approach that views interiors as living narratives fostering dialogues between people with dementia and their surroundings, enhancing their autonomy and well-being.
Traditional participatory methods often depend on verbal and visual cues to share ideas and receive feedback. However, with dementia, expressions may be less overt and more often reflected through nonverbal cues, requiring designers to interpret these subtle signals with the help of caregivers to truly understand the needs and preferences of people with dementia.
A key aspect of our approach involves integrating personal stories, and experiences into the design process. Accordingly, co-created spaces do more than function; they resonate with the personal histories of people with dementia, enhancing their quality of life and well-being.
The cognitive impairments associated with dementia raise significant ethical concerns regarding the potential biases and power imbalances in the design process. This challenges the researchers and designers to maintain an inclusive and equitable approach that respects the dignity and autonomy of all participants.
Furthermore, the study advocates for a shift towards fostering relational competence among designers, which is essential for interpreting the communications of participants, it helps guide the design process and stems from strong relationships between designers and people with dementia, which include their families, caregivers, and community.
Thus, this relational approach to participatory design emphasizes creating spaces that are not merely physical settings but are narratives themselves, facilitating ongoing dialogues

between individuals and their environments. This perspective ensures that the design process is not only about creating spaces but also about crafting stories that enhance the lives of adults with dementia. Through this approach, the research underscores the importance of an inclusive participatory process that respects the dignity and interconnectedness of all stakeholders, particularly those living with dementia

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-30“Finding ME through the Things”: creation of a toolkit for finding relationships between experience and objects for people with dementia

Natsumi Wada, Silvia Maria Gramegna, Alessandro Biamonti
Politecnico di Milano

This doctoral research presents methods addressing the intersection of interior design and homemaking practices to enhance the sense of belonging, dignity, autonomy, and identity in people with dementia.
In dementia care settings, the design of living environments can alleviate symptoms, promote well-being, and foster better living experiences. The relationship between environment and perception is crucial for individuals with dementia, as their perceptions are constantly changing. It is especially important to design spaces that evoke a sense of home to enhance these individuals' quality of life, autonomy, and well-being.
Methodology: focus group interviews, action research, tool making, and workshops.
The study began with a scoping review and included observations and interviews to understand the personal value of objects in care environments, using media like photos, plants, and drawings.
Findings: Interior design mirrors personal tastes and life experiences, fostering connections with cherished family memories and identity. After relocating into a care environment, recreating a sense of home, trust, and well-being is crucial for people with dementia, enhancing their quality of life.
Objects from home highlight how they represent a person's history, memories, and relationships, supporting their identity. The study developed a toolkit to translate individuals' sense of home, which is challenging to explore. This process was linked to autonomy and dignity.
Homemaking is linked to personal expression and autonomy, allowing individuals to inject creativity into their living spaces. Thoughtful interior modifications can support cognitive

challenges, enhancing comfort and familiarity for people with dementia.
Further findings: Creating a homemaking toolkit acts as a translation for cognitive change. Tailor the toolkit to individual preferences, involving family members. Encourage regular interaction with items to enhance belonging, stimulate memory, provide comfort, and increase independence. This approach can foster inclusive design practices that empower individuals with dementia to actively engage in creating and adapting their living environments.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-31From neglect to nurturing: the impact of primary care Cognitive Disorders Clinic on urban regeneration in Modena (Italy)

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AUSL Modena

Introduction: Urban degradation has emerged as a growing concern in numerous European cities, stemming from various factors and characterized by conditions of microcriminality. However, the introduction of public services in degraded areas has been shown to play a key role in their revitalization. In this context, the Cognitive Disorders and Dementia Clinic (CDCD) at the Local Health Authority (AUSL) of Modena stands as a relevant example of how healthcare services can positively impact the surrounding environment.
Materials and Methods: This case study focuses on examining the impact of relocating the CDCD to the R-Nord building in Modena in July 2023, with a particular emphasis on enhancing accessibility, visibility, and the ability to provide care for vulnerable individuals. Six months following the relocation, qualitative interviews were conducted with selected residents to gauge their perceptions of the changes brought about by the presence of the CDCD. Additionally, observations of police interventions during daylight hours were made, and experiential data on adverse events were collected.
Results: Police interventions decreased when comparing the six months before the opening of the CDCD to the six months following its establishment. Interviews with residents highlighted an appreciation for the CDCD's role in providing tangible support. Occasionally fragile individuals were identified and directed towards appropriate nodes in the social or healthcare network. The results indicate a significant improvement in overall urban degradation conditions in the R-Nord building of Modena following the establishment of the CDCD

Conclusion: This experience shows that healthcare services significantly improve safety and quality of life in degraded areas and highlights the need for multidisciplinary, collaborative approaches to urban degradation.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-32Identifying what people with dementia and their families need to feel supported by their local communities

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Background: Young onset dementia, i.e. diagnosed before 65 years, significantly impacts the individual, their families and wider society. For many people with young onset dementia, their primary needs are for practical, or social support, rather than medical interventions. Supporting social citizenship for people with young onset dementia means creating a place of belonging and allowing them to claim a place in the community. This research sets out to examine how people with young onset dementia can be supported to remain a part of their community, from the perspectives of people living with the syndrome and their family members.
Methods: A qualitative design was employed, using in-depth focus groups. Convenience and purposive sampling strategies were utilised. A total of 16 participants (six people with young onset dementia, and 10 family members) took part in six focus groups. Data were analysed using Reflexive Thematic Analysis.
Results: Three themes and eight sub-themes were identified. The first theme concerned the importance of community awareness of young onset dementia, which was identified as key in reducing stigma around young onset dementia and to better support people to participate in the community. The second theme was around wider issues impacting on engagement in communities and included loss of employment or meaningful occupation, access to entitlements and benefits, and social prescribing. The third theme concerned preferred supports, which included social and peer groups for young onset dementia, openness of existing community groups to members with young onset dementia, and local community centres or 'bases'.
Discussion: Harnessing community support for people with young onset dementia requires a

commitment to awareness and training; individualised approaches and social approaches; mapping and signposting of community supports; and making community supports more accessible for people.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-33Harnessing community supports for people with young onset dementia- focus groups with health and community workers. Getting everyone involved- It's everyone's business

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[1]University College Cork, [2]

Background: Existing services and supports available to people living with young onset dementia and their families are suboptimal and often inappropriate. Many people with young onset dementia identify their primary needs as being for practical and social, rather than medical, support. The study aim was to identify ways that community initiatives might be adapted to support people with young onset dementia.
Methods: Using a qualitative design, focus groups were held with 26 participants (16 healthcare professionals and 10 community workers) including Dementia Advisors, Social Workers, Community Development Officers, voluntary and community organisation representatives. Data were analysed using reflexive thematic analysis.
Findings: Three themes were constructed: (i) awareness, recognition and planning, (ii) ways community supports could be enhanced and (iii) examples of community-based supports. Findings called for increased clarity around existing community supports, and collaborative practice between health services and community groups, to foster access and inclusivity.
To enhance community supports, participants suggested a nominated point of contact, social rather than medical approaches, greater transport and connection within communities, and greater awareness and training on ways to support and include people with young onset dementia.
Initiatives discussed were primarily non-dementia specific, and include social community initiatives, Men's Sheds, music, arts and sporting organisations and also businesses that provide vocational opportunities. Inclusive practices include a nominated support person within community groups, dedicated times/spaces within public amenities such as libraries and museums, telephone support lines and communication cards.

Conclusions: Communities hold enormous potential to be part of the support system for citizens with young onset dementia. Social approaches encompassing accessibility and engagement, should be emphasised. Health and Social Care Professionals should utilise social prescribing to ensure connectivity between the person with young onset dementia and their local environment. Communities should be empowered to be aware and inclusive of people with young onset dementia.

Living with dementia - Housing and neighbourhoods

POS3. Posters - Living with dementia

POS3-34The development and implementation of Mobile Dementia Units (MDU): Athens Alzheimer Association case

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Athens Alzheimer Association

There are 50 million people living with dementia globally, a number that will increase dramatically in the future due to the increase of life expectancy in both developed and developing countries. According to recent statistics, in Greece 160,000 people suffer from dementia and 280,000 people have mild cognitive impairment. Alzheimer's disease and other forms of dementia cause high healthcare costs as a result of the increased needs for sufferer's treatment and care and support for family. The development and implementation of Mobile Dementia Units (MDUs) could support the role of other dementia services in Greece, usually based in urban areas and assist in dementia treatment and awareness raising. The aim of MDUs is to create a service delivery network in remote areas to meet the needs of families and people with dementia. In particular the aims include:a) the provision of specialized services at home to people with severe dementia living in remote areas, b) the education and support of their families, c) the creation of a network of services in remote areas with the cooperation of Health Centers, Rural clinics, Hospitals and Municipal social services.
The MDUs are considered a social innovation. Even if mobile units are not new to mental health services in Greece, specialized MDUs are the first time they come to meet the needs of remote areas and of people who are confined to their homes away from services.
The MDUs are funded by the Recovery and Resilience Fund.

Living with dementia - Art and dementia

POS3. Posters - Living with dementia

POS3-35Museum programs designed for people living with dementia and their care partners. The intervention in Portugal

Catarina Alvarez, Filipa Aniceto, Marta Carvalho
Associação Alzheimer Portugal

The WHO (2019) describes the benefits of art-based interventions as holistic, low-risk and highly cost-effective options for complex problems, such as dementia.
At national level, there are few museum programs designed specifically for People living with Dementia and their Care partners.
Alzheimer Portugal Association has been participating for several years in the implementation of these few existing programs.
In 2023, the Portuguese Network of Museums for Inclusion in Dementia (MID) was created to develop and share good practices, train the teams from these cultural institutions, and raise awareness in the community about dementia. Twelve entities are the founding members of the informal network, including Alzheimer Portugal. A brief description of the main goals and the governance model of this network will be presented.
With the aim of increasing the offer of these programs and based on international projects involving art and carried out in a museum context, such as Meet me at MoMa, the program "Marcar o Lugar – Encounters at the Museum" was created in 2021 in a partnership between Alzheimer Portugal and two museums – MAAT and Museu de Lisboa (EGEAC) - with the technical-scientific support of the Portuguese Catholic University, resulting in the creation of a manualized intervention model that can be replicated in other museums. Now, it's also being developed at the CCB Museum of Contemporary Art and at the Municipal Museums of Sintra. The replication is intended in more museums, prioritizing most disadvantaged regions.
Through the development and evaluation of this program, both quantitative and qualitative evidence points out to the enhancement of participant's mood and wellbeing during the sessions. The program also stimulates active involvement and participation; promotes social inclusion; fosters curiosity and creativity; and favors the development of significant relationships with other participants and with their care partners. The main results will be shared.

Living with dementia - Art and dementia

POS3. Posters - Living with dementia

POS3-36Creative minds in Mann: an evaluation of a creative arts project for people living with dementia and their carers

Jeanette Hogg
Hospice Isle of Man

Background: Therapeutic creative art interventions for people living with dementia (PLWD) and their caregivers. Joint funding bid from three agencies. Grant received from Arts Council to run an 18 month programme.
Aims: The opportunity to try something new
To reduce stress and promote PLWD and caregiver well-being
To reduce social isolation and loneliness
Methods: Six, two hour sessions delivered monthly to 12-20 people. Art sessions delivered by local artists and supported by the three partner agencies.
Artists to receive 'Dementia friends' awareness training prior to their session.
PLWD evaluation in each session using Canterbury Well-being Scale.
Caregiver evaluation at end of six sessions.
Artist evaluation at the end of each session delivered.
Results: 19 PLWD and 16 caregivers (Cohorts 1 & 2). Cohort 3 - summer 2024.
Most sessions rated as excellent or good.
"It is beneficial to meet with others and learn new skills. Relieves feeling of isolation"
"It is all good stuff, it helps you remember friendships made, making memories. Enjoyment, meeting people, helping conversation"
"We like the variety of activities within the programme".
Artists felt very well supported by health professionals and enjoyed running the sessions. All extremely likely to recommend the programme to other local artists.
"I very much enjoyed guiding the session and seeing how well everyone took to the medium. I would be very keen to continue providing these workshops to these groups"
"The session showed me how much music and community mean to both people with dementia and their families. Makes me want to do more of these".
Impact going forward: PLWD experienced improvements in feeling happy; feeling well; maintaining interest; confidence and optimism. "We would like to participate in a longer programme with an even wider range of activities"
Carers felt less isolated.
Limitations: Small sample sizes.
Funding constraints as 18-month programme.

Living with dementia - Art and dementia

POS3. Posters - Living with dementia

POS3-40It made me think about dementia in a totally new way - an art-abstract approach to reflecting on dementia

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In many regions of the world, neither the healthcare systems nor the staff are sufficiently prepared to care for people with dementia. The same applies to society's perception of these illnesses, which are often still dismissed as psychological changes.
In order to approach this topic, an arts-based research approach was used as part of an international and intercultural research project dealing with the care of people with dementia in Germany and the Dominican Republic. One of the main topics here was the question how orientation towards the space and the person can be positively influenced. The students were given the task of designing a dementia-friendly entrance door that they would individually recognize if they had dementia. Over a period of 4 years, around 120 different dementia-friendly entrance doors were designed by the students. The students were aged between 20 and 33.
Using the think aloud method, the students reflected on the challenges, but also the opportunities, in creating their doors. A key finding was that searching for and finding central themes in life is not trivial. Many of the students reflected that this exercise inspired them to reflect on their own history. At the same time, they also dealt with the history of their relatives, regardless of whether they already had dementia or not. All of the students reported that this task was the highlight of the international massive open online course.
From an intercultural perspective, there were clear differences between the doors of the Dominican and German students. While the doors of the German students tended to be limited to a few selected aspects, the Dominican doors were much more colorful and lively and included numerous culture-specific aspects, such as typical music or playing games. However, life in the family was central to the Dominican doors.

Living with dementia - Stigma and discrimination

POS3. Posters - Living with dementia

POS3-44Understanding and addressing dementia stigma and discrimination in underserved communities

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Objective: Understand experiences of dementia stigma and discrimination across underserved communities
Background: It is evident that dementia carries tremendous cultural stigma and discrimination. Too often, however, the discussion is homogenized and led by individuals with relative privilege. It is thus imperative to understand and bring attention to the realities of diverse and underserved communities who disproportionately experience stigma and discrimination – so that we can take a more nuanced, community centered approach to address it.
Methodology: This project captures stories from individuals across Black, Latino, Asian, and LGBTQ+ communities based in the US and Canada. Our qualitative primary research consisted of over 40 one-on-one interviews with people living with dementia and care partners. Secondary research included a literature review on the community's experiences.
Results: Across all four communities we heard experiences of both external discrimination and intra-community stigma.
Community members shared bias from health care providers delayed diagnosis and access to treatment and care – this was particularly notable when language barriers were present. Within care facilities, experiences of identity-based discrimination caused isolation and discomfort.
Within communities, the sentiment "we don't talk about mental health, let alone something like dementia" was common, though the underlying reasons varied across communities. Similarly, stigma around putting a loved one in a care home was deeply entrenched, but the reasons varied – from generational expectations to distrust of care institutions.
But we also heard how community members are addressing the issue – from standing up to health care providers to engaging in social media, support groups, and community education. Finally, we heard a call to action for how the border community can support.
Conclusion: Dementia stigma and discrimination is complex, multifaceted, and nuanced – and it is not experienced equally. We must understand how it manifests across diverse communities to improve outcomes for those most impacted.

Living with dementia - Stigma and discrimination

POS3. Posters - Living with dementia

POS3-45Co-producing blogs for a nursing audience – the impact of carer stories

Amy Pepper, Andrew Swindlells
Dementia UK

The Nursing Times is a monthly journal for nurses, published online and hard copy in the UK. Following a successful blog series focussed on dementia care and Admiral Nursing the editor expressed an interest in having the voice of a person with dementia or family carer to write about their experiences with the aim of educating nurses about the realities of living with and caring for someone with dementia. The authors of this abstract (an Admiral Nurse and a family carer) came together to write a series of blogs based on the experiences of caring for someone with dementia, with a focus on how that story could inform, inspire, and educate nurses who might meet people with dementia and their families in the course of their day-to-day practice.
In this presentation we will talk about the process of writing the blogs from the perspective of both Andrew (carer) and Amy (Admiral Nurse), the importance of the working relationship in bringing these blogs to life, some of the challenges of writing about a story that has been unfolding in real time, and the impact of these blogs on a nursing audience.

Living with dementia - Stigma and discrimination

POS3. Posters - Living with dementia

POS3-47Measuring dementia-related public stigma in the dutch general public: translation and validation of the dementia public stigma scale

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Background: People living with dementia may experience stigma related to their condition. Public dementia-related stigma is associated with lower quality of life and social isolation for people living with dementia. Valid measurement instruments of public dementia-related stigma are lacking in the Netherlands. We therefore aimed to translate and validate the 16-item Dementia Public Stigma Scale (DePSS) in Dutch.
Methods: A cross-sectional mixed methods survey was conducted among a nationally representative sample of the Dutch population (n = 524). A subset of the sample (n = 145) completed the DePSS again after one month. The DePSS has a 7-point Likert scale (1=strongly disagree to 7=strongly agree), and higher scores indicate greater stigma. Following validation guidelines we tested floor and ceiling effects, structural validity, internal consistency, and test-retest reliability. Additionally, for assessing content validity, open questions provided insights into respondents' perceptions of dementia and interactions with people living with dementia.
Quantitative results: The mean score on the overall scale was 3.41 (SD=0.64). The mean scores per factor were 3.04 (SD=1.09) for fear and discomfort, 4.55 (SD=0.89) for incapability and loss, 2.58 (SD=0.88) for acknowledgement of personhood, 3.61 (SD=1.24) for burden, and 2.30 (SD=1.07) for exclusion. No floor or ceiling effects were observed. A confirmatory factor analysis indicated an acceptable fit to the data (CFI= 0.952, RMSEA= 0.056, and SMRM= 0.064). The DePSS demonstrated high internal consistency (α= 0.82, ω= 0.79) and strong test-retest reliability for the overall scale (ICC= 0.82, 95% CI 0.76 – 0.89), with no significant difference between test and retest scores (t(144) = 0.135, p = 0.893).
We will present the results of the qualitative analyses during the conference.
Preliminary conclusion: The Dutch version of the DePSS appears to be a reliable and valid measure of public dementia-related stigma in the Netherlands.

Living with dementia - Empowerment and self-management

POS3. Posters - Living with dementia

POS3-49Empowering change: campaigning for improved rights and support for people living with dementia

Nigel Hullah
EWGPWD

Raising Awareness and Reducing Stigma: Effective campaigning initiatives are vital in raising public awareness about dementia, challenging misconceptions, and reducing stigma. Policy Reform and Legislative Advocacy. This includes lobbying for increased funding for dementia research, the development of national dementia strategies, and the implementation of dementia-friendly policies in various sectors such as healthcare, transportation, and housing.
Improving Access to Services and Support: Campaigns focus on improving access to dementia diagnosis, treatment, and support services, ensuring that individuals receive timely and comprehensive care.
Promoting Dementia-Friendly Communities: Campaigners work towards creating dementia-friendly communities that are inclusive, supportive, and accessible for people living with dementia.
Empowering People with Dementia and Caregivers: The campaign's efforts are Centered on empowering people with dementia and their caregivers, ensuring they have a voice in decision-making processes and access to resources that enable them to live fulfilling lives. This emphasis on empowerment underscores the campaign's focus on human rights and dignity.
Collaboration and Networking: Successful campaigning often relies on collaboration and networking among diverse stakeholders, including individuals affected by dementia, advocacy organizations, healthcare professionals, policymakers, and the wider community.
Evaluation and Impact Assessment: The campaign highly values transparency and continuous improvement. Therefore, its efforts should be systematically evaluated to assess their effectiveness and impact on policy, practice, and public attitudes toward dementia.
Campaigners can drive positive societal change and create a more supportive environment by advocating for policy reform, raising awareness, and empowering individuals.

Living with dementia - Empowerment and self-management

POS3. Posters - Living with dementia

POS3-50A good life with dementia is with personal assistance

Angela Pototschnigg

My greatest wish, as I live alone, is to live as long as possible in a self-determined way as I do now.
Personal assistance is offered in Austria in the disability sector, persons living with the

challenges caused by cognitive decline have not yet been included.
What does personal assistance mean to me?
Security, in my everyday life which has become more uncertain and even more unpredictable. It makes things possible that I consider important to live everyday life well and remain in command of it: medical consultations, official letters, support with the questions of what to do now, what my options are, etc. But also ordering tickets for an event and helping in the way of getting there. Personal assistance is the key to a good quality of life and to fight depression, because it ensures being flexible or spontaneous. If I avoid all activities my brain would remain rigid and everyday life would become more complicated and confusing. It is simply help with the things I can't do on my own – without losing face.
Personal assistance doesn't mean housekeeping or care service.
A lot of advice and support happens over the phone, but of course, we have personal meetings. I like to emphasize that so much is possible in our lives and can still be maintained with assistance - especially at the beginning of cognitive impairment. Activism and self-advocacy are unthinkable without personal assistance.
Let me also emphasize how important it is to prepare for the years in which the disease has progressed because my previous, healthy life is of little help to continue.
I could not have imagined a life like the one I am leading now, either as a healthy person or at the beginning of the illness.

Living with dementia - Empowerment and self-management

POS3. Posters - Living with dementia

POS3-51Seiglan, service and activity center of the Alzheimer's Association, Iceland. A new service resource for people in the early stages of dementia - a revolution in service

Harpa Björgvinsdóttir

Seiglan is an activity and service center for people who have been diagnosed with dementia and are at the stage of MCI (mild cognitive impairment) and their families, from diagnosis until more specialized resources are needed. Seiglan is a part of Alzheimer's Association in Iceland and was opened in early 2022, it is an entrepreneurship and the first of its kind in Iceland. Before Seiglan opened, a service was only offered to people who had reached the later stage of dementia, called specialized day training. The work that takes place in Seiglan is empowering and the service that is offered is on the terms of our clients. The aim of the

service is to slow down the progression of dementia, promote independence and increase activity by providing resources that stimulate physical and cognitive abilities, increase social participation and improve well-being. Seiglan is based on the ideology of occupational therapy where emphasis is placed on working with the individual's strengths, creating conditions for the clients to pursue their occupation and strengthening their social connections. The structure of our work is based on studies such as the Finnish FINGER study, which showed that physical, cognitive and social activity can slow down the progression of dementia and reduce symptoms. There is good cooperation between Seiglan and other professionals, which is necessary to form a holistic service around our clients and their families. It is important to reach people soon after diagnosis as they tend to isolate themselves, which can lead to little stimulation for body and soul and a gradual loss of self-confidence and the ability to control one's own life. During the time that Seiglan has been operating, it has become clearer how important the service is for this group and the need for more comparable resources necessary to reach the masses.

Living with dementia - Empowerment and self-management

POS3. Posters - Living with dementia

POS3-52France Alzheimer's Mutual Support group at the beginning of the disease

Lorène Gilly
France Alzheimer et maladies apparentées

The increasingly important requests that France Alzheimer’s local branches receive on a daily basis have led to the idea of formalizing actions that provide a response to the needs expressed by people at the start of their journey, just after the diagnosis, to be active in a project carried out for and by them.
Thus, in 2017, the “Living with dementia” program was designed on the model of therapeutic patient education, in the continuity of which the Mutual Support Group proposed by France Alzheimer is part.
The Mutual Support Group is based on support between peers with similar experiences and questions and aims to support and encourage people who are experiencing Alzheimer's disease in the realization of their projects and desires. It thus helps to restore their self-confidence despite their cognitive disorders and to enable them to regain better self-esteem.
It follows a cycle of 12 sessions (2-hours each), co-facilitated by the participants, and in

which volunteers and professional speakers linked to the content of the sessions get involved with people living with dementia. It has not for objective to decide for them but to support their own initiatives.
Each person living with dementia is an expert through their experience of the disease. Sharing it allows:

- the expression of their individual desires and abilities,
- to move in the direction they have defined by relying on each other, by collectively developing, and promoting creative leisure and cultural projects, projects stimulating,
- to maintain their cognitive and physical abilities.

The overall objective of the Mutual Support Group is to promote social bonds, the autonomy of people living with dementia and above all to enable them to create mutual aid, know-how and skills essential to a better life with the disease and to cope with their everyday lfe.

Living with dementia - Empowerment and self-management

POS3. Posters - Living with dementia

POS3-53Intergenerational programs for elderly and people with memory difficulties

Caterina Paolini[1], Chiara Barbanti[2], Felice Di Palma[3], Galli Chiara[2], Daniela Gariselli[4], Cristina Lazzari[2], Barbara Manni[2], Benedetta Mesini[5], Alessia Puglia[5], Barbara Ricchi[2], Romano Elisabetta[2], Tonino Rovatti[6], Sabrina Paganelli[7], Andrea Fabbo[2]
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Background: Dementia Friendly Community (DFC) is an international project created to support, coordinate and implement the dissemination of friends of people with dementia. In a DFC people will be aware of and understand dementia, so that people with dementia can continue to live in the way they want to and in the community they choose. Participation in intergenerational programs can have a positive impact on quality of life and well-being

across age groups.
Objective: The implementation of intergenerational activities aimed at raising awareness of dementia and creating friendly community settings for people with memory difficulties.
Methods: With the financial contribution of the Rotary Club, the purchase of tablets and cooking classes, 9 children from the Volta Institute in Sassuolo (MO) as well as two socialization centers in the area: Palestra della Memoria, which involves 25 elderly without cognitive impairment, and Officina della Memoria, the Meeting Center involving 30 people with Minor and Mild Major Neurocognitive Disorder. 5 meetings were held at the school to provide guidance on how to propose tablets and the use of APPs aimed at cognitive stimulation. 2 meetings were dedicated to the preparation of traditional Emilian dishes thanks to the collaboration of the association La Cucina Incantata. The meetings were coordinated by professionals (Psychologist, Occupational therapist, Nurse) afferent to the Cognitive Disorders and Dementia Center (CDCD) of the Ausl of Modena with the support of the team and volunteers. Young people will present a video to raise awareness among peers about their relationship with the elderly.
Results: Qualitative results: Older people ask when the children will return, exchanged phone numbers to stay in touch. This is an integrated care project with the municipality, health system and association that paves the way for future projects between schools and services for the elderly.

Living with dementia - Empowerment and self-management

POS3. Posters - Living with dementia

POS3-54MyWill workshop - Fostering empowerment in end-of-life care health care decision making

Meri Alaranta-Saukko, Ulla Kaikkonen
Oulun Seudun Muistiyhdistys

The MyWill workshop provides a comprehensive forum for individuals to address key aspects of end-of-life care and decision-making. Through a series of structured sessions, participants engage in discussions facilitated by experts and experts by experience. These discussions delve into the importance of advance directives, relevant legislation, and various models for documenting health choices. Presenters include professionals such as legal scholars and palliative care nurses. Additionally, the workshop offers diverse perspectives and practical guidelines.

The purpose of the MyWill workshop is to encourage individuals to express their opinions and ensure that their wishes are honored, even if they cannot directly communicate them. Participants learn about the significance of advance directives in guiding medical decisions, particularly in long-term care and end-of-life situations. They also receive information on the process of creating advance directives, including utilizing different digital platforms. Through interactive sessions and firsthand accounts from experts by experience, participants are equipped not only with knowledge but also a deeper understanding of advanced care planning and its emotional and practical impacts. The workshop promotes the discussion of these matters and encourages participants to start conversations with their loved ones, enhancing, clarifying, and unifying health-related decision-making.
Feedback from participants highlights the workshop's effectiveness in providing valuable information and promoting proactive engagement in advance care planning. Many express gratitude for new insights and the motivation to take concrete steps in documenting their wishes. Overall, the MyWill workshop serves as an important resource for individuals navigating the complexities of end-of-life care. It offers both education and empowerment, ensuring that the participants' voices are heard and respected in healthcare decision-making processes.

Living with dementia - Empowerment and self-management

POS3. Posters - Living with dementia

POS3-55Strategies of home-care services to support the personhood, citizenship, and autonomy of people with dementia living at home: a scoping review

Andrea Nakakawa Bernal, Andrea Nakakawa Bernal, Daniela Sangiorgi
Politecnico di Milano

This scoping review aims at mapping the strategies proposed by formal or community-based services to support the personhood, citizenship, and autonomy of people with dementia living at home. A growing emphasis exists on enabling older individuals, including those with dementia, to remain at home. Thus, it becomes crucial to understand how values such as personhood, citizenship, and autonomy are upheld within home care services. Despite the recognition of person-centered care as essential, operationalizing these values in practice remains challenging.

This study aims at understanding the strategies utilized by diverse home-care services to support these values in dementia care. A scoping review is being conducted adhering to PRISMA-ScR guidelines. The systematic search across four databases was conducted, including Medline, Scopus, EBSCO (Academic Search Complete, AgeLine, APA PsycInfo, APA PsycArticles, CINAHL Complete), and Web of Science resulted in n=2.394 hits after deduplication. A total of n=149 articles were selected for full-text review. Preliminary findings suggest that strategies to maintain personhood, citizenship, and autonomy are delivered by formal as well as informal caregivers. Specifically, respite services, music-based interventions, nature-based activities, and educational programs stimulating personalized daily activities (e.g., hair styling), conversation aids (e.g. to disclose diagnosis, to discuss palliative care), and self-management are among the most frequently employed strategies. Final results will also evaluate the overlap and/or (mis-)match within the field on which values are specifically targeted by each strategy to advance our understanding of person-centered dementia care. Ultimately, this study will provide a comprehensive overview of evidence, gaps, and attributes associated with supporting personhood, citizenships, and autonomy at the service level.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-01The potential applications of software supporting the early detection of cognitive disorders and dementia in diagnostics and prevention

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Introduction: The diagnosis of dementia is often delayed, which significantly worsens the prognosis. This poses several societal challenges, especially in terms of treatment and ensuring adequate quality of life. In Hungary, there is no available artificial intelligence algorithm that could help detect early signs of dementia based on the client's digital behavioral patterns.
Method: We used the PreDEM system for the early-stage assessment of dementia. In the two pilot periods, we gathered and analyzed over 8000 test data in 3 months in 2021 and over

11000 test data in 5 months in 2023. Participants completed the following tests: short international cognitive tests and games, Stroop tests, memory games, and other cognitive games. In addition, we compared various biomarker values. We created a standardized evaluation system for cognitive games to compare individual game results.
Result: Our results support the effectiveness of PreDEM. There was a significant difference between the results of individuals diagnosed with dementia and those from the healthy population. These differences will be well illustrated by the density functions of the results from various groups that we present. One of the highly significant observations during the study period is that cognitive game engagement notably improves individuals with memory issues. Many participants continued testing even after the study ended due to the pilot's success.
Conclusion: It can be stated that the PreDEM detected the first, otherwise imperceptible signs of dementia through artificial intelligence-based risk analysis. Early detection is vital as there's no cure; we must focus on improving conditions and monitoring through trend analysis. This allows for early intervention in case of a deteriorating trend. There is a need for preventive screening, as there is a clear correlation between preserved cognitive skills in later life stages and a reduced risk of Alzheimer's disease and dementia.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-02Feasibility and acceptability of implementing a collaborative service robot in long-Tterm care: staff experiences

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In long-term care (LTC) homes, staff are responsible to meet complex needs of people with disabilities. This task can be enhanced by integrating service robots equipped with Artificial Intelligence (AI) in care delivery. These robots offer personalized services for residents and empower the staff with efficient support. Despite growing interest, the implementation of service robots in LTC remains under-explored. This study investigates the feasibility and

acceptability of implementing a service robot, named Aether, in a Canadian LTC home, guided by the underpinning principles of Collaborative Action Research. We included interdisciplinary staff in pre- and post-intervention focus groups and conducted conversational interviews with residents, frontline staff members, and managers. Consolidated Framework for Implementation Research (CFIR) informed our implementation, data collection and analysis. We identified three key themes: 1) staff engagement and training; 2) robot features; and 3) environmental dynamics. The three facilitators, acronymized as AETHER, are: Appropriate Engagement and Training; Helpful robot features; and Supportive Environment and Resources. The three barriers are staffing crisis, non-customized robot design and limitations on resources and structural supports. Our results underscore the imperative of structural support at micro-, meso- and macro-levels for staff in LTC to implement technology effectively. This study contributes valuable insights into the future development and deployment of AI-enabled service robots in aged care settings.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-04Eye openers from four JAIN challenges and how we learn from each other

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Artificial Intelligence (AI) based support is a growing field in dementia but its use and acceptance can be much improved. The Joint Artificial Intelligence Network (JAIN) aims to promote worldwide affordability and use of AI based smart e-health products to contribute to the quality of life for people with dementia and their carers. One of JAIN's activities is the organization of yearly competitions for the best prototypes and products in the field of dementia. Alternately, a National (Dutch) and a Worldwide JAIN challenge has been organized, resulting now in four challenges. A scientific, professional and experience expert jury has collaborated in a review process to nominate the winners. Assessors reviewed among others the alignment with the JAIN mission, scientific evidence, ease of use, affordability and scalability. Different type of AI based smart products were submitted for participation and will be presented. Variations were found regarding applicability in the journey of dementia (from diagnosis to care in more severe stages), from daily use till use in

emergency situations, and technologies for people with dementia and/ or carers. Involvement of the target group was often lacking or insufficient. During the years the quality of information about the application improved and in the last World JAIN challenge the diversity of participating countries became richer. The JAIN challenges provide insight into the ongoing advancements and surplus benefits of AI-based support for people with dementia and their caregivers and also foster a continuous community of learning and development. One lesson learnt is that people with dementia and their carers should have a more central role in development of AI based smart solutions. The challenges were not only about innovation work, but showed a collective dedication to improving the lives of people living with dementia.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-05Towards AI-based digital biomarkers for early detection of dementia risk using mobile eye tracking

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Early detection of dementia risk by screening cognitive decline is fundamental for timely adaptation of lifestyle or interventions. We developed digital biomarkers estimating the degree of Mild Cognitive Impairment (MCI) using mobile gaze-based interfaces. We performed a pilot study enduring 4 months, engaging n=14 persons with MCI living at home with 12 females, 2 males, M=77.64 / SD=6.61 years of age, MoCA score M=24.14 / SD=3.14. The participants used a gamified version of the antisaccade test (MIRA; Levy et al., 2004; Paletta et al., 2020), an emotionally weighted object tracking task (EMO; Paletta et al., 2020), and the psychomotor vigilance task (PVT; Dinges & Powell, 1985). During interaction, 30 Hz eye-tracking was extracted from an embedded camera using VisualCamp software. Participants were asked to use apps once a week. The results demonstrate statistically significant Spearman correlations between MoCA scores (Nasreddine et al., 2005) and derived eye movement features (EMF), such as, (1) fixation duration (MIRA;

r=.419; p=.017*), (2) blink rate (EMO; r=-.507; p=.004**), as well as with (3) mean reaction time (PVT; r=-.508; p=.005**). Furthermore, an AI-based digital biomarker was developed using machine learning-based regression models. The model of Support Vector Machines with linear kernel estimated the MoCA total score from EMF input with an absolute error of M=2.487 points. The MIRA app was played M=2.46 / SD=3.63 times per week demonstrating high adherence. These results of digital biomarker development indicate successful steps towards frequent use of mobile gaze-based cognitive assessment. These playful assessment apps offer a promising potential for future long-term monitoring in dementia prevention, early detection as well as in numerous dementia care services.
Acknowledgments: This work was supported by Eurostars (grant No. 115629) as well as by the Innovative Health Initiative Joint Undertaking (IHI JU; grant agreement No 101132356) and their associated partners.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-06Personalising domiciliary dementia care via co-designed computational matching: a study protocol

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The delivery of person-centred dementia care in community settings is undermined by high levels of care worker stress, burnout, and turnover. Improving the experience of domiciliary care for all stakeholders is paramount. Previous research suggests that matching the skills and characteristics of care workers to the needs and preferences of people living with dementia can enhance the quality of domiciliary care. This study aims to personalise domiciliary care through the co-design and development of an empirically informed novel Web platform that, through machine learning, matches the preferences of people living with dementia, to their family/friend supporters and care providers. It will also enable 'live', needs-informed rostering. Our study is novel in how it will enable evidence-informed and co-production-based design, meaningfully and extensively involving people living with dementia throughout. This interdisciplinary study will consist of three work packages

(WPs): WP1 - a review summarising evidence on what 'good' domiciliary care is for key stakeholder groups; WP2 - eight focus groups with key stakeholder groups of community-dwelling people with dementia, their supporters, and domiciliary care professionals; and WP3 - the iterative co-design of the platform, which will involve co-design workshops with representatives from key stakeholder groups, iterative development of the computational elements of the platform, and development of the interface. Intersectoral costs and outcomes will be considered throughout the project, which will inform a full economic evaluation in the future. We will document the development process, and pursue additional funding for further development and pilot-testing of the prototype. The study will commence in September 2024 and is jointly funded by the National Institute for Health Research and the Alzheimer's Society.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-07Data-driven discovery of associations between prescribed medication and dementia risk: a systematic review

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Background: Recent successes in clinical trials of drugs which can slow dementia progression have led to renewed focus to find more effective and safer treatments. One way to identify plausible candidates is to utilise large clinical datasets to see if any currently prescribed medications are associated with altered risk of developing dementia. Method: We conducted a systematic review to identify studies adopting a data-driven approach to investigate the association between prescribed medications and dementia risk. Literature searches were performed in MEDLINE, Embase, and PsycINFO without methodological filters or language restrictions. Titles, abstracts and full texts were screened independently by two reviewers with discrepancies resolved by a third where necessary. The Prediction model Risk Of Bias ASsessment Tool and the Joana Briggs Institute checklist tools were used to assess risk of bias and methodological quality. Medications were categorised

according to the Anatomical Therapeutic Chemical classification. We included 14 studies that used administrative or medical records data from more than 130 million individuals including 1 million people diagnosed with dementia. Despite a lack of consistency between studies in identifying individual drugs which modify risk of Alzheimer's disease or all-cause dementia, some themes emerged for drug classes with biological plausibility including antibiotics, antivirals and vaccinations (reduced risk) and anti-psychotics, antidepressants and medications for cardiovascular disease and diabetes (increased risk). Conclusion: Drug repurposing for use in preventing or treating dementia is an urgent priority and our findings can be used to prioritise candidates for disease modification trials, and provide a basis for further exploration of available datasets/studies.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-09Quality of life of people with dementia residing long-term care: a study using natural language processing to analyse observational data on daily activities

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Background: Quality of life (QoL) of people with dementia is of utmost importance. However, understanding QoL of people with dementia could be challenging as they may find it difficult to recognize and communicate their needs; interviews and questionnaires often may be unsuitable. Observing daily activities of people with dementia could enhance our understanding of their QoL. Manually analysing large amounts of data gathered by observations, and the corresponding textual comments, can be time-consuming and complex, leading to under-utilization of this data for novel insights. Artificial intelligence (AI), such as natural language processing (NLP), an innovative AI method that enables computers to understand human language, can make this process more time efficient. This study aims to provide novel insights into the QoL of people with dementia by analysing quantitative and qualitative data related to activities of daily living using AI methods. Methodology: The Maastricht Electronic Daily Life Observation Tool was used to capture quantitative data on people with dementia's mood, activity, and social interactions. During observations, unstructured field notes detailing the behavior and environmental influences

on people with dementia were recorded. In addition, QoL questionnaires were administered to caregivers of people with dementia. NLP extracted relevant QoL information from the unstructured field notes by topic clustering: Together with the quantitative data from the observations, these will be related to the reported QoL. Results are expected mid-2025 and will include a correlation between, on the one hand, quantitative observed data and data from the field notes, and the reported QoL in questionnaires on the other hand. Conclusions: Study aims to enhance the understanding of QoL for people with dementia in long-term care by employing AI, including NLP, to observational data and corresponding field notes. Over time, as results are analysed, this approach could lead to interventions better tailored to individuals' needs.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-10Harnessing linguistic features and automatic speech recognition to identify alzheimer's disease in speech

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Background: Speech and language changes have been identified as early symptoms of Alzheimer's disease (AD). The study of these changes and their automatic detection and analysis have the potential to be used in large epidemiological studies as a real-time, non-invasive, and inexpensive diagnostic method. Methodology: We use a publicly available benchmark dataset of audio recordings from 156 English-speaking participants completing a picture description task (78 people with AD, 78 healthy controls). We have implemented two methods of machine learning to automatically distinguish between the two groups: a) We extract discriminative linguistic features from transcripts, and train a Random Forest (RF) classifier to distinguish between AD and control, and b) We fine-tune a pre-trained BERT language model to classify transcripts. We evaluate these approaches using the Area under the ROC curve (AUROC), and we study the effect of using three systems of Automatic Speech Recognition (ASR) for transcription in this context. The use of ASR would enable potentially fully-automatic end-to-end use cases. We quantify transcription errors using Word Error Rate (WER) and assess their effect on linguistic features and AD detection performance. Results: AD classification performance is best when using manual transcriptions, but remains strong when using ASR-generated transcriptions, achieving an

AUROC of 0.87. Linguistic features + RF are more robust when faced with transcription errors than BERT, with additional advantages in explainability. Conclusions: In a new and independent study, we collect speech samples and neuropsychological test scores on 1000 healthy older participants. We aim to study the connection of cognitive performance and language use, hoping to find features of speech that might indicate early cognitive decline. Our vision is to monitor intra-individual changes in speech to automatically detect prodromal symptoms of developing dementia, allowing for early medical treatment and optimal support.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-11Detecting Aβ pathology with integrated machine learning approaches and plasma measures

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University of Eastern Finland

Background: The pathophysiology of Alzheimer's disease (AD) involves the accumulation and aggregation of β-amyloid (Aβ). Accurate identification of Aβ pathology is crucial for diagnosing AD and enrolling suitable participants in clinical trials aimed at assessing disease-modifying treatments. However, current methods for measuring Aβ protein levels, such as positron emission tomography (PET) and cerebrospinal fluid (CSF) biomarkers, are invasive, costly, and not feasible for widespread screening efforts. Methodology: To address this limitation, we propose a novel machine learning-based model by combining Random Forest with a Naive Bayes classifier to detect CSF/PET Aβ positivity. We aim to identify PET/CSF Aβ positivity using plasma biomarkers in conjunction with other non-invasive measures, including MRI data (volumetric and thickness measures), demographics, APOE4, and cognitive measures in the Alzheimer's Disease Neuroimaging Initiative dataset. Results: The 10-fold cross-validated area under the curve (AUC) was 0.87 for the PET-based and 0.86 for the CSF-based Aβ positivity detection models. The methods with and without MRI data exhibited similar performance for both PET and CSF Aβ positivity detection. The relevance of the models for predicting changes in clinical status was also validated. The CSF-based model achieved an AUC of 0.79 for predicting MCI (mild cognitive impairment)/dementia conversion in cognitively normal (CN) individuals and an AUC of 0.82 for predicting dementia conversion in MCI individuals over 4 years. The PET-based

model achieved an AUC of 0.75 for predicting CN to MCI/dementia conversion and an AUC of 0.77 for predicting MCI to dementia conversion. Conclusions: The innovative computational models for detecting Aβ positivity provide an opportunity to assess Aβ pathology in a non-invasive and cost-effective way, which might facilitate AD drug development, early screening, clinical diagnosis, and prognosis evaluation.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-12Exploring plasma biomarkers in predicting cognitive decline rates in early stage of Alzheimer's disease

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Background: Accurately predicting the rate of cognitive decline is crucial for understanding disease progression and guiding personalized interventions in Alzheimer's disease (AD). This study employs machine learning approaches to predict the rate of cognitive decline based on four summary measures (memory, executive functioning, language, and visuospatial) from the Alzheimer's Disease Neuroimaging Initiative (ADNI) dataset. Methodolog: Our primary focus lies in investigating the role of plasma biomarkers in conjunction with other non-invasive measures, including MRI data (volumetric and thickness measures), demographics, APOE4, and neuropsychological scores (baseline summary measures). The methodology initially utilizes elastic-net linear regression on MRI data and then combines the MRI-derived predicted value with other predictors using a random forest regression approach. By integrating different data types, our goal is to accurately estimate the trajectory of cognitive decline in the early stages of Alzheimer's disease, in a cohort of individuals with healthy and mild cognitive impairment statuses. Results: The 10-fold cross-validated correlation scores between predicted and actual rates of cognitive decline were 0.50 for memory score, 0.49 for language score, 0.42 for executive functioning, and 0.44 for visuospatial score. Upon examining the importance of different predictors, MRI score demonstrated higher importance compared to plasma biomarkers for predicting the rate of cognitive decline. Interestingly, among the three plasma biomarkers, NFL and P-tau181 exhibited higher importance compared to the Aβ42/Aβ40 ratio. Conclusions: This study significantly contributes to advancing our understanding of AD progression by leveraging machine learning techniques with diverse data modalities.

The developed predictive model holds promising potential for informing clinical decision-making, enabling early interventions, and ultimately enhancing patient outcomes in Alzheimer's disease.

Innovation in care and research - Artificial intelligence

POS4. Posters - Innovation in care and research

POS4-13From crisis to connection: evaluating the legacy of COVID-19 on technology adoption and social interactions in elder care homes

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Background: The Covid-19 pandemic, which began over three years ago and still echoes to this day, significantly impacted society, disproportionately affecting people with dementia, especially those in care homes. The pandemic was anticipated to be a transformative period for the use of social technologies in care homes, with expectations that technology-mediated interactions, such as video calling, would become standard practice. This study investigates the long-term effects of the pandemic on social interactions and emotional health within residential elder care, focusing on the perspectives of care staff, families, and residents. Methods: An online survey was conducted to assess the current state of social bonding and emotional support in residential elder care post-pandemic. Care staff (n=35) were invited to share their opinions and experiences. The survey focused on technology-mediated efforts to sustain social bonds and support emotional health as part of daily care routines and aimed to identify drivers and barriers to the sustained adoption of technology. Results & Discussion: The findings reveal persistent barriers to the lasting adoption of technology in care homes, such as usability problems, digital literacy gaps, and infrastructure limitations. Despite these challenges, the pandemic has led to a greater focus on person-centered care, with residents now more prominently considered in care practices. While many residents have either passed away since the pandemic or forgotten about the lockdown, care professionals reported experiencing distress and negative memories related to isolation during the pandemic. Concerns about recurrence, lack of information, and hesitation to engage in physical touch to prevent contamination were noted. Conversely, the crisis underscored the

value of care staff's skills and expertise, reinforcing the belief that the human aspect of caregiving should take precedence over strict adherence to medical protocols. These insights emphasize the importance of balancing technological solutions with personalized, human-centered care in post-pandemic dementia care practices.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-14Using reminiscence therapy to support dementia patients in an ambulance environment

Alison Johnstone

The Welsh Ambulance Service provides unscheduled and planned services, including telephone and online advice. We support people affected by dementia as they access, use and move through our services. We have introduced a digital solution providing reminiscence therapy for dementia patients, who may become stressed and anxious in our environments. We receive safety reports, staff and patient feedback where our environments including vehicles, processes, and staff interactions have an impact on experiences and outcomes of people living with dementia when in our care. A lack of communication, reassurance and support, particularly in an emergency, can be distressing, confusing and cause anxiety. “Develop a connection with me. Talk to me about what I like and don’t like, the more you know about me the better”. “Listening to music and being distracted by different things will help”. Research tells us that people living with dementia benefit from distraction and occupation, which has led to the introduction of reminiscence therapy. Reminiscence Interactive Therapy Activities (RITA) is a digital solution using evidence-based therapies to develop more meaningful interactions with dementia patients. The resources in the software can provide distraction activities and different sensory experiences, including music, relaxation, games, films and more. We know that these opportunities support patients and carers on a long journey, on a long delay outside hospital or those who just require distraction due to boredom, distress, confusion or pain. Case studies demonstrating the impact of RITA: On a 5 hour wait on the ambulance, the patient thoroughly enjoyed playing games and listening to the music which brought back good memories, and allowed them to sing along, remembering most of the words. The patient loved listening to music and humming along. They were becoming restless whilst waiting but once we started using the tablet their mood settled.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-15Application of the DEMIGNED principles in usability evaluations – findings from evaluating an academic memory clinic's mobile website

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Background: Declining skills associated with dementia pose challenges for successfully using digital health technologies (DHT). To address this, the DEMIGNED principles have been developed to guide the design of DHT and enhance their usability for people living with dementia. In addition to design guidance, their application in usability evaluations methods (UEMs) could be valuable, especially in expert-based approaches. A rapid and relatively cheap expert approach can identify usability problems that can be addressed before essential usability testing with people living with dementia. Yet, to determine the use of the DEMIGNED principles in an expert test, the realness of usability problems that experts capture assessing a user-interface against these principles needs to be determined. Methods: A heuristic evaluation, an expert UEM, was conducted where five usability and domain expert-evaluators assessed the user-interface of the mobile website of Alzheimer Center Amsterdam, a tertiary academic memory clinic, against the DEMIGNED principles. Data was analyzed through deductive thematic analysis. Subsequently, think-aloud sessions were conducted with people visiting the memory clinic, encompassing those living with subjective cognitive decline, mild cognitive impairment, or dementia. Usability problems from the think-aloud sessions were mapped onto the findings from the heuristic evaluation and newly identified usability problems were analyzed separately. Results: The heuristic evaluation identified 36 unique usability problems, while think-aloud sessions with seven memory clinic visitors revealed 28 unique usability problems. Eighteen usability problems were identified in both methods. Common usability problems were associated with using the search function, content organization, scrolling, information overload, and clarity of system feedback. Conclusion: This study shows the potential of applying the DEMIGNED principles in expert testing, as it determined that 50% (18/36) of the unique problems identified by the expert-evaluators can be considered "real" usability problems. Future research should explore the applicability of DEMIGNED principles in usability evaluations across various DHT.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-16It brings me outside - using virtual reality with older adults living with dementia in canadian long-term care homes

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Virtual reality (VR) is promising in improving the well-being of people with dementia in long-term care. With the emerging number of studies on VR use with people living with dementia, few studies focused on the impact of VR on personhood. Limited studies included participants living with a later stage of dementia and from diverse cultural backgrounds and family support in VR sessions in LTC. Our study aims to explore how VR addresses the psychosocial needs and personhood of people living with dementia in LTC. A virtual reality program (using head-mounted devices and a tablet) was implemented in three Canadian LTC homes. Twenty-four residents with cognitive impairment or different stages of dementia participated in individual or group VR sessions over four to six months in 2023. Other study participants included three family members and 21 interdisciplinary staff. We applied video-ethnographic methods, including conversational interviews and observations with video recording while residents were using VR. Data were also collected through family interviews, staff interviews, focus groups and field notes. Our interdisciplinary research team includes people living with dementia and family partners, frontline staff, trainees, and researchers. Thematic analysis was performed, guided by the five psychosocial needs - comfort attachment, occupation, identity, and inclusion. In conclusion, virtual reality can be a complementary tool to sustain identity, enhance the sense of belonging to the community, and support meaningful activities and positive social experiences for persons living with dementia and having diverse needs in LTC. Based on the learnings, our team proceeds further with two co-creating VR projects with residents, family and staff in long-term care homes and hospital settings. We explore further participants' preferences, needs, possibilities and impacts of co-creating technology programs in healthcare settings.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-17Let's play: staff insights on gamification as a catalyst for exercise in long-term dementia care

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Background: Gamification holds potential to motivate older adults with dementia to engage in exercise by transforming physical activities into enjoyable and fun experiences. By embedding gaming elements in cycling exercises, it may foster a sense of interest and achievement, and potentially improve health outcomes. Purpose: This study investigates the staff perspectives on using a digital game to motivate cycling exercise among residents in a Canadian long-term care (LTC) home. Methods: Utilizing an interpretive description approach, we conducted focus groups with 20 staff members including recreational staff, nurses, and care aides. The consolidated framework for implementation research (CFIR) guided the data analysis to identify potential barriers and facilitators to the adoption of the digital game. Results: Barriers such as hearing and cognitive impairment pose significant motivational and physical challenges. Current strategies employed by health staff included persistent engagement, building personal relationships, varying exercise routines, incorporating music, and passive exercise equipment. Challenges in implementing the cycling game include dealing with physical limitations and health-related concerns. Cultural and individual relevance of the exercise program were seen as crucial facilitators for its acceptance and success. Conclusion: The integration of gamification in exercise for older adults with dementia in LTC settings shows promise but requires careful consideration of the various facilitators and barriers identified by staff. Successful implementation will rely on tailoring interventions to meet the specific needs and preferences of residents while addressing the identified challenges to maximize engagement and health benefits.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-18Recommendations to prioritise and address existing and future challenges in assistive technology for people affected by dementia: a delphi study protocol

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Introduction: The INTERDEM Assistive Technology taskforce members are conducting a Delphi study to identify existing and future challenges concerning development, usability, cost-effectiveness, implementation, and ethics in assistive technology for people affected by dementia. This Delphi study will explore recommended actions and priorities to address these challenges. Methods: A two-round electronic Delphi study will be conducted. Members of INTERDEM and people in their networks, including researchers, health and social care professionals, people living with dementia and their support persons (approximately 250 people) will be invited to take part. Informed consent will be obtained before each round. Views and feedback from Patient Public Involvement (PPI) contributors will be gathered prior to the commencement of the first round in September 2024. The first round of the Delphi survey will include statements prepared based on the 2017 INTERDEM position paper, a scoping review, and a mapping exercise conducted by the INTERDEM Assistive Technology Taskforce. The statements will be related to the challenges observed and solutions to address them. The participants will be asked to rank the statements and add their contributions in open field comments under the statements. Once the responses are collected, they will be analysed using quantitative (frequencies, mean) and qualitative (thematic analysis) methods. The consensus will be established when a 75% agreement has been reached. The open-field comments will be used to revise existing statements where needed or to develop new statements to circulate in the second round. Discussion: This Delphi study will identify the existing and possible future challenges with assistive technology for people affected by dementia and contribute to the development of recommendations to prioritise and address these challenges. We aim to publish our results in early 2025, which will contribute to the new INTERDEM position paper on assistive technology: priorities for research and practice 2025-2032.



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New horizons – Innovating for dementia
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Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-19Relationship between cognitive functioning and everyday technology use: a cross-sectional study in people with cognitive impairments

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Objectives: In older adults with cognitive impairments, cognitive decline may interfere with everyday technology (ET) use. It is currently understudied which cognitive functions are especially relevant for using ETs. This study investigates the relationship between cognitive functions and i) the perceived ability to use ET and ii) the amount of ETs that are relevant to people with cognitive impairments. Method: Fifty-one participants (n=25 with mild cognitive impairment; n=26 with subjective cognitive decline; 61% female; mean age 70.9) were recruited and completed 17 neuropsychological tests assessing processing speed, attention/ concentration, language/ verbal skills, motor skills/ construction, perception, memory, and executive function. Perceived ability and relevance of ET use was captured with the short version of the Everyday Technology Use Questionnaire (S-ETUQ). S-ETUQ data were processed using a Rasch model. A correlation matrix using Spearman's rho and interaction modelling were applied for the main analyses. Results: There was a significant correlation between the perceived ability to use ET and executive function (Trail Making

Test B, rs(49)=-.43, p<.01) and language performance (Boston Naming Test, rs(49)=.45, p<.01). Moreover, there was a significant correlation between the perceived relevance to use ET and visual memory skills (Rey complex figure immediate (rs(49)=.29, p=.038); Rey complex figure delayed recall (rs(47)=.32, p=.024). Conclusion: The findings highlight that certain, and few, cognitive functions may be linked to ET use, yet this relationship appears complex and evidence in the field remains limited and inconclusive. To understand ET use and capture a person's experience holistically, healthcare professionals are advised to combine neuropsychological tests, self-reports, and observations in the future.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-20Specific navigation patterns: the exploration of user engagement of a website to support advance care planning in dementia

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Background: Web-based tools have gained popularity to inform and empower individuals in advance care planning (ACP). We have developed an interactive website tailored to the unique needs of people with dementia and their families who support ACP. This website aims to break away from the rigid pathways shown in other tools that support ACP, in which ACP is shown as a linear process from information to reflection, communication, and documentation. Aims: To assess the website's usage by people with dementia and their family caregivers, identify distinct user engagement patterns, and visualise how users navigated the website. Methods: We analysed the website's log data obtained from an eight-week evaluation study of the site, which included participants with dementia and their family caregivers. Interactions collected in the log data included visiting web pages or clicking on hyperlinks. Website usage was assessed by analysing the log data. Distinct user engagement patterns were identified using K-means clustering. Process mining was applied to visualise user pathways through the website. Results: Throughout the eight-week study, users spent an average of 35.3 (SD = 82.9) minutes over 5.5 (SD = 3.4) unique days on the

website. It was mostly the family caregivers who used the website, with only three people with dementia using it independently. Three distinct engagement patterns emerged: low, moderate, and high. Low-engagement participants spent less time on the website during the 8 weeks, following a linear path from information to communication and documentation. In contrast, moderate and high-engagement users demonstrated more dynamic patterns, frequently navigating between information pages, communication tips, and interactive tools to facilitate exploration of ACP-related aspects and the question, "What matters most to you?" Conclusion: Users' varying navigation patterns underscore the importance of ensuring smooth transitions between different website sections, challenging the conventional linear ACP representations found in other web-based tools.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-22A scoping review on digital tools for dementia prevention, diagnosis, and needs and preferences for people in pre-dementia stages: an ABOARD study

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Background: In near future, a gap is expected between the growing demand for Alzheimer-related healthcare and a shrinking workforce. Digital tools are thought to have a mitigating effect. This scoping review aims to identify brain health-related digital tools for diagnosis, prevention and needs and preferences, with people in pre-dementia stages as primary end-users. Additionally, insights into maturity and evaluation of these tools, study sample diversity, and future directions are gathered. Methodology: PubMed, IEEE Xplore, Ovid, and Web of Science were searched in January 2023. Two independent reviewers screened 2811 records on title and abstract, and subsequently 408 full text articles, based on in- and exclusion criteria. Articles on tools targeting those with an Alzheimer's disease or dementia diagnosis were excluded. Results: We included 39 articles, encompassing the categories diagnosis (4/39), primary prevention (15/39), secondary prevention (10/39), daily life support (6/39), wellbeing (2/39), and decision aids (2/39). Variation in study sample emerged regarding cognitive abilities and education (healthy (11/39); mild cognitive

impairment (11/39), (subjective) cognitive impairment (10/39); 'no dementia' (1/39); variation of cognitive abilities (6/39); and >50% high education: 13/39). Less variation was found regarding sex (>50% female: 27/39) and age (>50% >60 years: 23/39). Few reported on ethnicity (12/39) and digital literacy (11/39). Most tools were in an early evaluation and maturity stage (37/39; 94.9%), mainly comprising prototyping (13/37) or pilot testing (22/37), efficacy testing (23/37), feasibility testing (13/37) and usability testing (12/37). Suggestions for future directions comprised enhancing sample diversity to ensure inclusivity and conducting longitudinal large-scale RCTs to assess clinical evidence. Conclusions: The evidence on maturity and evaluation for digital tools for people (at risk) in pre-dementia stages is preliminary and further research is needed before health care providers and policy makers can implement such digital tools. Future research should ensure inclusive tool development, health equity, and effectivity.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-23"Who's responsibility is it, actually?" a study on multi-stakeholder collaboration in the development of assistive technology for elderly with dementia

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Assistive technology holds promise to increase autonomy and independence of elderly with dementia, and can relieve the gap between the growing need for care and the decreasing amount of healthcare professionals. Yet, the impact of assistive technology (specifically those that help with everyday activities) remains limited. Many of the assistive technologies that are developed do not reach the go-to-market stage or fail to find customers. Of the technologies that do, a plentitude is not successfully implemented and thereafter not adopted in practice. The development and implementation of these technologies affect different stakeholders with fluctuating degrees of involvement throughout the process. Researchers are typically most involved in the earliest stage of development, whereas entrepreneurs are

more involved as the go-to-market stage approaches. Healthcare practice (including end users) in turn often tends to find the technology only when it is on the market. Research however shows that collaboration between these stakeholders throughout the technology lifecycle, including in early development, can aid the implementation and adoption of these technologies. This, in turn, can increase the impact of these technologies on the daily lives of elderly with dementia. While the field has seen an increasing interest in engaging end users in technology development as individuals (i.e. co-design), there is limited understanding of stakeholder collaboration on an ecosystem level. Therefore, an interview study was conducted with the three stakeholder groups: researchers, entrepreneurs and care practice. The interviews focused on attitudes and perspectives on one's own and others' role and responsibilities in the development of assistive technology. Results reveal contrasting views on the ownership of the technology development process and stakeholders' goals in participating in it. Future design research should investigate how to overcome these barriers for a more reciprocal and collaborative design process, to increase successful implementation and adoption of technology in the long run.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-24"How do you stay in touch with your relative?" reflections on a field study of telecommunication with people with dementia during COVID-19

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Four years after the global upheaval of COVID-19, we can reflect on the impact the pandemic had on how we care for people with dementia. What have we learned about communication from a distance, and what are the impacts of these lessons on the care we

provide now? This study portrays the experiences of elderly with dementia and their relatives in keeping contact during COVID-19. Interviews were held during a period in which care homes were closed off. With earlier research indicating the potential of telecommunication technologies in fostering social connection, this study focused on the unique types of telecommunication, facilitators and barriers for using them and needs for actual use. Results affirmed that calling, video-calling and messaging were successful in aiding communication. However, formal caregivers appeared indispensable to setting up the technology. Skills and interest in its use – for both family members and formal caregivers - were therefore vital. Availability of the technology at care facilities revealed to be another facilitator, as was an awareness of the facility's day structure for family members to find a right time during the day to call. Overall, telecommunication appeared especially successful in fulfilling the need of family members to be reassured their relative with dementia was doing well. As was already expected then, in-person visits we again know now however remain superior. In-person contact is more effective in assessing well-being of a loved one and through this in providing a sentiment of reassurance. Moreover, in-person visits allow for activity-steered conversation, adding meaning to contact, especially at a later stage of dementia. These factors diminish the need for telecommunication in current times. Nonetheless, in light of potential future pandemics or for family members living remotely, such technologies have proven their potential and can, when overcoming the described barriers, help increase social proximity.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-25Does multi-user VR have a place in the home for people living with dementia and their support person?

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Virtual reality (VR) is gaining attention as a digital technology to support the social health of people living with dementia. However, there is a paucity of research exploring how VR is applied in the home environment. This is particularly important given the high number of people living with dementia residing in the home and the value of supporting this population

to age in place. This research aimed to explore the feasibility, acceptability and usability of a multi-user VR application for use in the home to promote or maintain the social connectedness of people living with dementia and their support person. The application was trialled over two home sessions with five people living with dementia and their five support persons. Qualitative insights were gathered through observational field notes and semi-structured interviews. Reflexive thematic analysis guided the analysis process. The findings will focus on the aspects specifically related to VR use in the home, its potential usefulness for social connectedness, the feasibility of using the hardware and software in this context and future directions for VR use in the home environment. The findings provide formative evidence into the potential use of a home-based multi-user VR application for people living with dementia and their support person, and sets the agenda for future work in this area.

Innovation in care and research - Assistive technologies

POS4. Posters - Innovation in care and research

POS4-26Towards tech equity in dementia care: navigating issues of representation and access

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Background: This paper explores the complex relationship between technology, dementia care, and the needs of a diverse aging population. It examines how technological solutions can propagate inequalities across linguistic, cultural, and socio-economic divides, yet at the same time offer innovative solutions to overcome barriers in dementia care. In this paper, we focus on issues of access and representation in technologies aimed to support people with dementia. Method: A scoping literature review was conducted across PubMed, Scopus, and IEEE Xplore to identify studies on technology, dementia, diversity, and accessibility. Selection criteria included works discussing technology in dementia care, emphasizing accessibility, representation, and potential impacts on diverse populations. "Representation" refers to the inclusion and depiction of diverse groups in technological solutions, considering cultural, linguistic, cognitive, and physical characteristics. Data extracted

included technology types, population demographics, outcomes, and barriers to access and representation. Results and Discussion: The findings reveal that technology in dementia care can both perpetuate inequality and offer innovative solutions. On one hand, biases in AI tools and digital platforms can limit accessibility for marginalized groups, such as those from diverse cultural backgrounds or with varying literacy levels. On the other hand, AI-based summarization tools and real-time voice translation technologies can bridge communication gaps and make health information more accessible. Emerging technologies like VR and social robots can provide personalized and culturally sensitive interventions. The review highlights the importance of inclusive design and interdisciplinary collaboration. Input from people with dementia and other stakeholders is crucial to developing technologies that meet diverse needs. The review calls for efforts to improve accessibility, mitigate biases, enhance representation in user research, and leverage innovation to create equitable dementia care solutions, ultimately improving the quality of life for people with dementia across diverse communities.

Innovation in care and research - Preparing for new AD treatments

POS4. Posters - Innovation in care and research

POS4-27Immunotherapy targeting plasma ASM is protective in a mouse model of Alzheimer’s disease

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Acid sphingomyelinase (ASM) has been implicated in neurodegenerative disease pathology, including Alzheimer's disease (AD). However, the specific role of plasma ASM in promoting these pathologies is poorly understood. Herein, we explore plasma ASM as a circulating factor that accelerates neuropathological features in AD by exposing young APP/PS1 mice to the blood of mice overexpressing ASM, through parabiotic surgery. Elevated plasma ASM was found to enhance several neuropathological features in the young APP/PS1 mice by mediating the differentiation of blood-derived, pathogenic Th17 cells. Antibody-based immunotherapy targeting plasma ASM showed efficient inhibition of ASM activity in the blood of APP/PS1 mice and, interestingly, led to prophylactic effects on neuropathological features by suppressing pathogenic Th17 cells. Our data reveals insights into the potential pathogenic mechanisms underlying AD and highlights ASM-targeting immunotherapy as a potential strategy for further investigation.

Innovation in care and research - Preparing for new AD treatments

POS4. Posters - Innovation in care and research

POS4-28Memory encoding of verbs and transcranial direct current stimulation (tDCS) in amnestic MCI

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TDCS has been shown to improve memory performance in people with Alzheimer's disease, particularly for nouns. In contrast, processing of verbs has rarely been studied in this group, although their impairment may be an early predictor of this disease [1]. In this double-blind, sham-controlled study, we investigated whether a 3-day tDCS in people with MCI has an effect on their memory performance for verbs. 20 participants were divided into 2 groups based on several cognitive-linguistic tests (10 healthy controls (HC), Ø=78y; 10 persons with MCI, Ø=81y). The two groups differed significantly in their cognitive and verbal memory performance. Additionally, the MCI-group showed lower processing speed during trail making and lower retrieval performance in non-verbal memory. On three consecutive days, all participants had to memorize 40 randomized verbs in 4 lists and then recall them freely, either combined with 20-min tDCS (2mA) or sham application. The anode was placed left inferior-frontally, the cathode right suprarorbitally [2]. Both the MCI and the HC-groups treated with tDCS were able to recall more words on day 3 than the sham-groups. However, while participants in the HC-group benefited highly significantly from tDCS, the variance between participants in the MCI-group was high, preventing cross-group significance. Due to its excellent tolerability and applicability in the home environment, tDCS is an effective reinforcement of therapeutic intervention to maintain verbal memory performance for longer [3,4]. However, it is very important to check whether a person with memory disorders responds to tDCS or not and, if necessary, to adjust the stimulation parameters individually. [1] Williams, E, McAuliffe, M, Theys, C (2021) Brain and Language 223, 105041; [2] Heimann F, Weiss S, Müller HM (2024) Frontiers in Aging 4,1171133; [3] Balduin-Philipps, LS, Weiss, S, Müller, HM (2022) Aging, Neuropsychology and Cognition 29(2); [4] Wollenberg M, Weiss S, Müller HM (2024) Aphasiology

Innovation in care and research - Preparing for new AD treatments

POS4. Posters - Innovation in care and research

POS4-29Dual amyloid beta/tau vaccine PRX123 surrogate results in robust clearance of amyloid plaques in brains of aggressive APP/PS1 mouse model

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Objective: To evaluate in vivo efficacy of nonclinical surrogate PRX123 (PRX123s) – a dual amyloid beta (Aβ)/tau peptide vaccine against the N-terminus of Aβ and MTBR-tau – in a transgenic mouse model expressing human amyloid precursor protein (APP) and with aggressively high Aβ pathology. Background: Accumulation of Aβ plaque and tau tangles throughout the brain are hallmarks of Alzheimer's disease (AD). Clinical evidence demonstrates that N-terminal anti-Aβ antibodies capable of robustly reducing Aβ plaques in brains of patients with AD can slow cognitive and functional decline. Nonclinical evidence indicates that anti-MTBR-tau antibodies can potentially suppress the pathogenic spatiotemporal spread of tau. It is hypothesized that simultaneously disrupting these pathologic processes may increase therapeutic benefit beyond removal of Aβ plaques alone. Vaccines targeting Aβ and tau may prevent or delay the clinical manifestation of AD by generating long-term polyclonal responses capable of intercepting both pathologic processes simultaneously. In nonclinical studies, PRX123s generated robust immunogenic responses, producing antibodies that promote clearance of Aβ plaques and neutralization of MTBR-tau in vitro. Design/Methods: APP/PS1 (Thy1-hAPP*V717I/Thy1-hPS1*A246E) transgenic mice were vaccinated with PRX123s, beginning at 3.5 months old for 6 months. Results: PRX123s generated robust antibody titers capable of binding Aβ plaques and tau tangles in post-mortem AD brain tissue at antibody concentrations expected to be reached in the brain (0.3% of plasma concentrations). Immunohistochemical analysis of brain tissue from vaccinated APP/PS1 mice demonstrated significant reduction in cortical Aβ plaques compared with a nonsense peptide immunized control group. The degree of plaque clearance achieved with PRX123s immunization was similar to a plaque-clearing N-terminal monoclonal antibody, used as positive control. Conclusions: These data demonstrate that PRX123 may generate high-quality antibody responses capable of clearing Aβ plaques at brain exposures that may be achievable in patients and support the continued development of PRX123 for the treatment and/or prevention of AD.

Innovation in care and research - Preparing for new AD treatments

POS4. Posters - Innovation in care and research

POS4-30From a bibliometric meta-analysis to a tangible reality: the conception of the HUB Alzheimer Barcelona

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According to United Nations estimations, Spain will reach 25% of its population aged 65 years or over in 2030 and by 2050 this figure will be above 35%. Therefore, it is expected that our society will take the necessary steps to prepare for the upcoming challenges of an aging population. One important pillar of this strategy is investing in both basic and clinical research but the private and public funding of science in Spain falls below the economic efforts of fellow EU countries. Despite this underfunding for the first time, in 2021, a commissioned bibliometric study demonstrated the existence of a powerful research nucleus on Alzheimer's disease (AD) in the city of Barcelona. The power of the research carried out in Barcelona, at a great distance from any other city in Spain, is such that it places Catalonia and Spain in global leading positions. At present, the Pasqual Maragall Foundation (PMF), in coherence with its Purpose, Mission and Values, has promoted the articulation of the HUB Alzheimer Barcelona as an attempt to dynamize joint research activities through the collaboration of different public actors. Currently, the seven founding members are PMF and its research institute (Barcelonaβeta Brain Research Center), Fundació ACE, Hospital Clínic, Hospital del Mar, Hospital de la Vall d'Hebron and Hospital Sant Pau. The Hub started its activities with a joint meeting celebrated in May'24 gathering 12 experts from all the member institutions together with key participants from the Catalan Government Health Institute to discuss the challenges facing the implementation of biological therapies to treat AD. We are also building an inventory of research infrastructure and clinical data-bases to increase synergies and accelerate research. At the HUB, we are convinced that together we ensure high impact research that will give answers to the foreseen challenges that our society faces.

Innovation in care and research - Preparing for new AD treatments

POS4. Posters - Innovation in care and research

POS4-31Development of small molecules promoting tau clearance in Alzheimer disease

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Introduction: Now, two anti-amyloid antibodies aducanumab and lecanemab have been approved for Alzheimer disease (AD). However, controversies still exist regarding their safety and substantial economic burden. They also have restricted brain delivery and could not pass through intact neurons to target intracellular proteins. There is an urgent need to develop new drugs for AD. A major pathological hallmark of AD is the intracellular accumulations of neurofibrillary tangles composed of tau paired helical filaments (PHFs). Lowered efficiency of degradation pathways, such as ubiquitin proteasome system, further exacerbates the aggregated tau accumulation. Proteolysis-Targeting Chimeras (PROTACs) are hetero-bifunctional molecules that can bring E3 ligase into the vicinity of protein of interest, leading to protein ubiquitination, followed by proteasomal degradation. Since 2016, PROTACs have been applied to resolve tau pathologies. Most of these PROTACs have only been evaluated in cell models and the exploration is still at the early stage. In this study, we aim to perform intensive research to develop novel small-molecule PROTACs to initiate tau degradation for AD treatment.
Methods: We screened a library of tau binders from a public database (bindingdb.org) by performing global molecular docking into the 3D structure of PHFs. The top ranked compounds were selected to design new PROTACs, with different linkers connected to the ligands binding to E3 ligase, for instance cereblon and carboxyl terminus of Hsp70

interacting protein (CHIP). We are performing modeling of the ternary complex (tau-PROTACs-E3 ligase) and the highly scored PROTACs will be synthesised. Their protein binding affinities and tau-reducing effects will be evaluated in different cell models. Results: We perform the development of small-molecule PROTACs according to the methods listed above. We selected the top ranked tau binders and designed new PROTACs. Conclusion: The hit PROTACs will move on to animal study and provide pre-clinical evidence for novel treatment of AD tauopathies.

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-32Family experience in using telepresence robots with residents in long term care

Lillian Hung, Grace Hu, Joey Wong, Haopu Ren, Annette Berndt, Sarah Kleiss, Lily Wong, Ali Hussain, Jim Mann

Background: Informal care, often provided by family or friends, remains a hidden and underrecognized undertaking within long-term care (LTC) settings. As people living with dementia move into LTC, their care partners face a difficult role change from primary caregiver to visitor, losing a significant degree of control and direct care involvement. The COVID-19 pandemic exacerbated these challenges with health risks, changing care home protocols, and government policies. Objective: To help address these challenges, this study aimed to investigate the experiences of care partners who used telepresence robots to maintain contact with and care for their loved ones during the pandemic. Methods: This study was guided by the Collaborative Action Research (CAR) approach). Along with interdisciplinary researchers and trainees, our research team includes patient and family partners as co-researchers throughout the project. We conducted semi-structured interviews with 20 care partners (family members) who used the robots in five urban Canadian LTC homes between May 2021 and August 2023. Results: Thematic analysis identified four key themes characterizing their experiences using the robot: 1) Decreases care partner burden, 2) Facilitates care partner-staff relationship, 3) Creates relational autonomy, and 4) Expands the scope of what is possible. Conclusion: The results of the study suggest that telepresence robots can play a useful role in enhancing the caregiving experience for informal care partners in multifaceted ways. Care partners reported positive benefits of having the robot

assist their virtual visits. However, further research is needed to determine the sustainability of robot implementation among diverse geographic regions and care home compositions.

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-33Integrated intervention of psychogeriatric care (INTRINSIC) services in Greece: design, iterative development and single-site pilot study findings

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Background: INTegRated InterveNtion of pSychogerIatric Care (INTRINSIC) program was developed in order to address the mental and cognitive healthcare needs of older adults residing in low-resource areas of Greece. Older adult mental and cognitive health services remain mainly embedded in tertiary- or secondary hospital settings, despite the fact that communities in low-resource areas are aging. Those services are not always easily accessible by older adults, living in such communities. The program aimed to form Integrated Digitally enabled mental and cognitive care services, easily accessible by all. Methods: INTRINSIC was developed and piloted in three iterative phases: INTRINSIC initial version conceptualization, a field testing in Andros island; and Extending the services. The INTRINSIC program initial version relied on a digital platform easy to use by health care professionals, enabling videoconferencing, a flexible battery of diagnostic tools, pharmacological treatment, psychosocial support and the active involvement of local communities involved in service shaping, through Research Users' Groups. Results: Preliminary data showed that in 61% of the 119 participants of the pilot study, new diagnoses of mental and/or neurocognitive disorders were established. The implementation of INTRINSIC resulted in a significant reduction in the distance that patients needed to travel and time spent to visit mental and cognitive healthcare services. Based on feedback

and gained experiences, a new digital platform, facilitating e-training of healthcare professionals and public awareness raising, and a risk factor surveillance system were created, while INTRINSIC services were extended to incorporate a standardized sensory assessment and the modified Problem Adaptation Therapy. Conclusion: The INTRINSIC model may be a pragmatic strategy to improve access of older adults, with mental and cognitive disorders living in low-resource areas, to healthcare services. The program was granted extension by the Greek Ministry of Health, under the umbrella of "Greece 2.0 - National Recovery and Resilience Plan"

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-34Telehealth-delivered acceptance and commitment therapy interventions for family caregivers of people with dementia: insights from a systematic review and clinical trial

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Introduction: With the increasing prevalence of dementia, the number of family caregivers has also risen, highlighting the urgent need for evidence-based psycho-social interventions. In recent years, there has been a growing demand for interventions focusing on self-management strategies for family caregivers of people with dementia. Subsequently, Acceptance and Commitment Therapy (ACT) emerges as a promising psycho-social intervention to address the unique challenges faced by these caregivers. Methods: A systematic review and subsequent clinical trial were conducted to identify and address the shared needs of family caregivers of people with dementia through an ACT-based intervention. A systematic search of five databases was undertaken to explore the potential of ACT for this population. Subsequently, a single-arm clinical trial involving 30 caregivers comprehensively evaluated the feasibility and intervention efficacy of a 9-week web-based self-help program based on ACT, supplemented with online coaching sessions. Results: The findings of the systematic review revealed that ACT holds promise as an approach to address the shared needs of family caregivers of people with dementia. Building upon these findings, the clinical trial demonstrated significant improvements in stress, anxiety, and

depressive symptoms, alongside enhanced psychological flexibility and acceptance. However, caregivers reported challenges in maintaining new self-management skills during unpredictable and uncontrollable situations, such as during behavioural symptoms of the person with dementia. Conclusion: The interconnected findings of these three studies highlight the potential of telehealth-delivered ACT interventions in supporting family caregivers of people with dementia. Human contact and personalisation strategies emerge as crucial factors for optimising intervention feasibility and efficacy. Further research, including larger-scale controlled trials, is warranted to validate the effectiveness of these interventions and consolidate our findings aimed at improving caregivers' well-being. Reference of the review: https://doi.org/10.1016/j.cpr.2023.102341; Reference of clinical trail part feasibility: 10.2196/53489; Reference of clinical trail part efficacy: currently under revision

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-35Demedyacare: an occupational telerehabilitation program for caregivers of people with dementia to increase their coping abilities and reduce burden

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Careapt

Introduction: People with dementia (PwD) require high levels of care, most of which is provided by either family or informal caregivers.Psychosocial interventions have demonstrated to reduce caregiver burden and delay nursing home admission.Telemedicine could ease access to such interventions enabling caregivers to increase their health literacy, sense of competence and emotional resilience and keep their care recipient at home. Method: Through a co-design process involving geriatricians,psychologists,neurologists, nurses,occupational therapists and 25 dyads,a telerehabilitation program has been developed and tested through a 12-months Beta Test protocol.The program comprises a multidimensional clinical assessment followed by a telerehabilitation plan.Occupational therapists act as care manager interface towards caregivers through a telemedicine platform

embedding a set of clinical assessment tools, with the support of a multidisciplinary team. Results: 22 out of 25 caregivers were spouse or children.79% were female and 59% lived with the care recipient in the same household.Average age of caregivers was 63,72 and Zarit index 36,88.Average PwD's age was 83,75, Barthel Index 61,27, IADL 0,97, NPI Index 24,86 with 4,8 BPSD.The program required on average 18,8 sessions per caregiver. 48%of telerehabilitation sessions addressed BPSD, 17%provided emotional support, 14% ADL adaptation, 11% nurse interventions for comorbidities and 10% other issues (communication and cognition).16 dyads were evaluated at T0 and T1 (after 6 – 15 months): NPI Index decreased from an average of 24,1 to 19,2/144. Irritability was the most significant BPSD and it improved in frequence and gravity.Caregiver burden (Zarit Burden Inventory) improved on average 12%from T0 to T1.NPI stress improved in every domain too, except for feeding.A self-developed questionnaire was administered by phone with 24 responders out of 25. 88%reported increased health literacy,87%improved sense of competence and 97%felt emotionally supported. Conclusion:Our main target was caregivers' BPSD understanding and mitigation aimed at burden lowering. Further investigation in terms of clinical outcomes are required.

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-36Motivational interviewing in caregiver counseling

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Caregiver counseling plays a vital role in supporting family caregivers, and Motivational Interviewing (MI) presents an opportunity to positively influence challenging home care situations. MI, a conversational technique, aims to bolster an individual's self-motivation and readiness for change while facilitating and supporting that change. Despite its proven effectiveness in various contexts worldwide, MI has yet to be applied in caregiver counseling. This study aims to introduce MI into the care counseling domain by creating and implementing a training program titled "Motivational Interviewing in Caregiver Counseling." The development of this training program followed an evidence-based methodology and utilized a participatory action research approach. Various stakeholders, including nursing professionals, MI experts, psychologists, and researchers, were involved in the development process. The training program consists of 24 teaching units, each lasting

45 minutes. It incorporates an e-learning component for theoretical knowledge and an in-person group training for practical application, utilizing role plays, case vignettes, exercises, discussions, and feedback. The implementation and evaluation of the training are ongoing. The training and first results will be presented.

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-37The information and training needs of informal caregivers of people living with dementia: a literature review and empirical study

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Background: Informal caregivers deal with stressors related to care activities and the difficulty reconciling them with daily life. There is extensive literature on caregivers' unmet needs and the effects on their well-being, as well as on patients' outcomes such as early institutionalization, low quality of life, and mortality. While existing reviews mostly deal with caregivers' needs and interventions to address them, scientific evidence on caregivers' information needs and educational programs is more recent. Aims: As part of the project AGE-IT (PNRR PE8 "Age-It"), we aimed to identify information and training needs of informal caregivers of people with dementia. Methods: A literature review on this issue was carried out. Simultaneously, two focus groups with informal caregivers (N=19), and a workshop with NGOs were conducted in Italy. Qualitative data transcription was performed by using NVivo, and data were analysed using inductive thematic analysis. Findings: The literature review revealed four areas of information needs: (a) disease; (b) patient care provision; (c) healthcare services; and (d) caregiver self-care. Focus groups data analysis revealed three themes. The first theme concerned with the diagnosis, its emotional impact and need for support. The second theme dealt with caregivers' need for reliable information and valid support, due to the lack of information provided by professionals, and the presence of conflicting information from different sources (e.g., web, books). The third theme concerned the contents and style of the desired e-learning platform. Findings from the literature review and focus groups were grouped to generate the core contents to be included into our e-learning platform to inform and support informal, formal caregivers and migrant

care workers. Conclusions: Without prior knowledge and training in dementia care, it is very difficult to cope and adapt to caregiver roles, and providing information and education is crucial to ensure high-quality care for people with dementia.

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-38Perceptions and experiences of remote cognitive assessments and computerized interventions in elderly as part of the remote memory clinic

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Background: As the population ages, cognitive impairments and dementia are emerging as challenges. Accurate diagnosis and treatment are crucial, but access to specialized clinics for dementia screenings is often difficult especially in rural and isolated areas. Telemedicine offers a promising solution, providing access to cognitive testing opportunities. This research line aims to delve deeper into the subjective experiences of elderly patients, focusing on their perceptions and feelings towards digital technology, particularly in remote cognitive assessments and Computerized Cognitive Training (CCT) as a home-based intervention. Methods: Study1 involved elderly participants with cognitive impairments participating in a tablet-based CCT. Participants were assigned to training, active control (watching documentaries), or waitlist control groups, with 10 weeks of CCT. Subjective parameters such as patient-reported outcome measures and user experience were evaluated, providing insights into how participants perceive and interact with CCT. Planned Study2 will employ telemedicine for remote cognitive assessment of patients conducted via videoconferencing. Data will be analyzed for acceptability and user experience, focusing on subjective perception of remote memory clinic settings. Results: In Study1, significant improvements in self-perceived cognitive performance were reported. Across all groups, dementia worries decreased significantly, and quality of life improved non-significantly. CCT was rated as satisfying in terms of entertainment, indicating a positive user experience. Study2 results are expected by Oct-2024. Conclusion: Study1 underscores the potential of CCT in enhancing subjective cognitive performance and reducing dementia worries. The

results highlight the feasibility of CCT in a home setting, with positive usability and acceptability ratings reflecting subjective experience and perceived efficacy. Study2 will explore the use of telemedicine for remote cognitive assessment. We aim to deepen our understanding of experiences and feelings towards digital technology. This approach provides an examination of remote cognitive assessment and training from the patients' perspective and considers patient experiences in the digital development.

Innovation in care and research - Telehealth and remote care

POS4. Posters - Innovation in care and research

POS4-39Behavioral and neuronal substrates of serious game-based computerized cognitive training in cognitive decline

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Background: Subjective cognitive decline (SCD) has predictive value towards Alzheimer's Disease (AD) and lends itself as target for non-pharmacological preventive interventions such as serious game-based computerized cognitive training (CCT). However, investigations of CCT show heterogenous results in slowing age-and disease-related cognitive decline and adherence to training protocols remain a challenge. The aim of this RCT was to comprehensively evaluate CCTs' effectiveness, integrating control conditions and neurophysiological as well as blood-based biomarkers. Methods: In this bi-centric RCT with parallel groups, 155 participants (mean age 72.2) with cognitive impairment ranging from SCD to mild AD were randomized to three arms, comparing CCT to an active control condition (watching documentaries) and a waitlist control condition. Both active arms entailed a three-month intervention period comprising a total of 60 at-home sessions (5 sessions per week) and weekly on-site group meetings. To assess longitudinal effects, the intervention group only completed additional 6 months of at-home training with monthly on-site booster sessions. As biological markers, blood-based amyloid levels (pre intervention) and structural MRI (pre and post intervention) were assessed. Results: Significant improvement over time was observed in aggregated domain specific composite scores of

episodic and semantic memory and spatial abilities. However, there was no significant interaction between groups and timepoints. Adherence to the training protocol was consistently high across timepoints and groups (4.87 sessions per week). There was no significant change in grey matter volume. CCT's effectiveness was not moderated by amyloid levels. Conclusion: This RCT indicates no specific advantages of a three-month CCT intervention on cognitive or biological outcomes. However, long-term cognitive improvements and the high rates of adherence warrant the inclusion of CCT in successful multicomponent interventions.

Innovation in care and research - Clinical trial recruitment and retention

POS4. Posters - Innovation in care and research

POS4-40Permission to contact: evaluating a recruitment strategy for the neuroprogressive and dementia network (NDN) in Scotland

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Our presentation highlights how the developments of recruitment tools are the key to increasing research participant numbers in the Neuroprogressive and Dementia research Network (NDN) in Scotland. Recruitment and retention of participants in clinical studies remain the key components of conducting successful research. Our presentation illustrates how, over the last eight years, the NDN have sought to recognise and adapt to the challenges of actively recruiting participants to studies. We will explain how Permission to Contact (PTC) has provided people with dementia or a neurodegenerative disease the opportunity to take part in our research in a user-friendly and efficient method of contact and recruitment. This presentation also explores the barriers and facilitators of PTC, our user-friendly method designed to inform interested participants about research studies being conducted across Scotland. We will outline other recruitment tools used across the NDN to facilitate recruitment to Dementia and neurodegenerative disease clinical research. We will show how the NDN Patient and Public Involvement group is at the core of the NDN, and in the design of PTC, with a full review of the PTC forms contents, wording, and approval of the final draft. We strongly believe that the active inclusion of people with lived experience of a health condition in the design, development, and execution of research is essential. We will highlight the number of PTC participants and their associated disease categories, extracted from the PTC online database. All data is anonymised. Our primary results demonstrate the

value of using PTC as a recruitment strategy for NDN studies, especially in comparison to other methods. For most studies, PTC was the primary source of recruitment with the clinician referral method accounting for the rest. We compare the utility of PTC across several sites across Scotland within the wider NDN network.

Innovation in care and research - Clinical trial recruitment and retention

POS4. Posters - Innovation in care and research

POS4-41Key stakeholder engagement and protocol development for the IHI-funded public-private partnership project PREDICTOM

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Background: To address global healthcare challenges, collaborative efforts among universities, companies, patient organizations, and regulators are vital. This abstract presents the journey for protocol development for a multicentral clinical research. PREDICTOM, a project led by Stavanger University Hospital and GE Health, through the European Commission (EU) Innovative Health Initiative. PREDICTOM aims to develop an AI-driven platform for Alzheimer's disease risk screening. Method: The protocol development included five key steps, (i) development of research idea based on current gaps, (ii) identification of diverse key stakeholder groups (researchers, clinicians, industrial partners and, importantly, public involvement experts) (iii) consultations with expert panel and key stakeholder, (iv) implementation of feedback from key stakeholder groups and experience from preparing previous clinical studies (RADAR-AD, PROTECT), and (v) input from the operations team (IT developers, programme managers and research coordinators) working on the ground floor to set up study logistics, liaising with industry (testing and selecting

biomarkers, identifying technical requirements and planning logistics for data collection and dataflow) and establish the legal framework. The initial research idea was identified and developed (January 2023), this process included two in-person meetings with researchers, clinicians and industrial partners (January and February 2023) and weekly online meetings to develop the application until submission (May 2023). The project received approval in July 2023 from EU with clear work packages to address key aims. The initial draft of the protocol was written post face-to-face meeting in August 2023, with the first draft being ready by the kick-off meeting in November 2023, followed by the first ethics approval in January 2024. Conclusion:Protocol development of large public-private partnership projects is a highly challenging process requiring the collection and integration of information from many key stakeholders.

Dementia researchers of the future: Innovative approaches to dementia

POS4. Posters - Innovation in care and research

POS4-42Identifying motivators and barriers in the vaccination process for people with dementia and their carers in the United Kingdom: an online survey study

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Background: People with dementia (PwD) encounter elevated risks of infectious disease complications and higher mortality rates. Carers play a pivotal role in their vaccination decisions and are a prioritized group for vaccination. Therefore, it was crucial to include them in our study. We examined the perceptions, acceptance, and factors influencing COVID-19 and influenza vaccination among PwD and their carers in the United Kingdom (UK).
Methods: A cross-sectional online survey study was conducted in the UK from January to March 2024, recruiting most participants through the Join Dementia Research (JDR) platform. The survey, developed for the purpose of the study, covered demographics, medical history, and attitudes toward influenza and COVID-19 vaccines. Descriptive, chi-square and multivariable regression analysis were used to assess predictors for accepting influenza and COVID-19 vaccination.
Results: A total of 316 carers (mean age=59.5; 86.4% for people with late-onset dementia)

and 235 PwD (mean age=71.7; 61.7% people with late-onset dementia) completed the survey. Both groups identified access as the primary barrier to vaccination. Carers and PwD declared that people should not be vaccinated due to exposure to the infection directly gives the best protection (6.3% and 8.1% respectively). 12% of carers stated some PwD should not be vaccinated due to concerns about mental capacity or vaccine effects on dementia, while only 6.4% of PwD shared this view. Over half (53.8%) of carers believed their vaccination-related thoughts and behaviours influence those of the PwD they care for. 13.6% of carers were uncertain about healthcare providers recommending vaccination for PwD.
Conclusion: Similar motivators and barriers affect the vaccination decision of PwD and their carers/supporters. Both reported resolvable difficulties and/or barriers to the vaccination process (e.g., access, inconsistent information about vaccination, concerns about ingredients in vaccines). Certain and understandable information and access support might boost vaccination rates and satisfaction for both groups.

Dementia researchers of the future: Innovative approaches to dementia

POS4. Posters - Innovation in care and research

POS4-43Evidence-based third-wave cognitive behavioral therapies for informal caregivers of people with dementia

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Background: Informal caregivers of people with dementia often encounter challenging emotional and psychological difficulties during the caregiving process. Third-wave cognitive-behavioral therapy (CBT) integrates acceptance and mindfulness into traditional CBT, focusing on how individuals relate to their internal experiences rather than the content of these experiences. Unlike traditional CBT, which targets the alteration of negative thoughts and emotions in terms of their form or frequency, third-wave CBT emphasizes the importance of the individual's connection with their internal experiences. Various process-oriented methods have emerged within third-wave CBT, including Acceptance and Commitment Therapy (ACT), Dialectical Behavior Therapy (DBT), and Mindfulness-Based Cognitive Therapy (MBCT).
Aim: The aim of this study is to analyze and evaluate the effectiveness of third-wave CBT

applied to informal caregivers of people with dementia.
Method: We are conducting a systematic literature review. We are electronically searching for articles published in English over the past 10 years (May 2014-May 2024) across databases including PubMed, PsycInfo, MEDLINE, CINAHL, Scopus, Web of Science, and the Cochrane Library. The procedure for study selection and data analysis is informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. We are assessing the methodological quality of the included studies using the Joanna Briggs Institute (JBI) Critical Appraisal Checklists for Experimental and Quasi-Experimental Studies.
Preliminary results: The literature demonstrates that third wave CBTs have positive effects on caregivers of people with dementia. These interventions can help caregivers reduce their stress levels, maintain emotional balance, and improve their overall quality of life. Additionally, they can promote psychological flexibility and more effective coping with challenging situations among caregivers.
Conclusion: Third-wave cognitive-behavioral therapies aim to enhance caregivers' coping skills, increase acceptance and mindfulness, support emotional balance among informal caregivers of people with dementia. However, further research is needed to evaluate the effectiveness of these interventions more comprehensively.

Dementia researchers of the future: Innovative approaches to dementia

POS4. Posters - Innovation in care and research

POS4-49Effect on sleep, diet, and exercise on dementia caregivers

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The current descriptive study explores the sleep, diet, and exercise patterns among 114 caregivers, whose mean age was 55.7 years, with 72.8% being women.
Results indicate significant sleep dysfunction: 37.2% of caregivers reported rarely or never feeling rested upon waking, and 46.5% did not get enough sleep, with 45.6% sleeping only 5 to 5.5 hours on average. Sleep latency was also prevalent, as 33.3% required 16 to 30 minutes to fall asleep. Dietary habits showed reliance on coffee, with 69.4% consuming it daily. Meat consumption was reported by 75%, and 60.9% ate pasta, indicating common dietary preferences. While 86.2% had 1 to 3 meals per day, 100% of the caregivers supplemented their diets with vitamins. The physical activity level was low, with 62.3% of

respondents reporting no exercise in the past week.
These findings underscore significant health concerns among caregivers, including sleep deprivation, inadequate nutrition, and physical inactivity. The study emphasizes the need for targeted interventions to promote self-care practices that can enhance caregivers' health, including better sleep hygiene, balanced nutrition, and regular exercise.

Dementia researchers of the future: Innovative approaches to dementia

POS4. Posters - Innovation in care and research

POS4-53Effects of serious games on improving cognitive function among seniors with a diagnosis of Alzheimer's disease. Reports from a pilot study

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Objectives: The goal of the project was to test a research procedure and evaluate the impact of regular playing in serious games (games aimed at learning new skills or training existing ones) on the cognitive functions of seniors with a diagnosis of Alzheimer's disease.
Material and methods: Three seniors (a man and two women) with a diagnosis of Alzheimer's disease played two tablet computer games for 12 weeks - “Sea Hero Quest” based on navigation skills and “Wood Block Puzzle” based on spatial imagination and logical thinking. Cognitive abilities were assessed using Addenbrooke's Cognitive Examination-III (ACE-III) scale before interactions and immediately after the intervention.
Results: Individuals' overall ACE-III scores were 67.73 and 81 on the first trial and 83,78,85 immediately after the game, respectively
Conclusions: All participants achieved improvements in ACE-III scores. Importantly, improvements were observed in the memory scale (both in encoding and extracting information). This is particularly important for people whose greatest cognitive difficulties are related to memory. Further studies on a larger group of participants are needed to fully confirm the positive effects of serious games on cognitive function.

Dementia researchers of the future: Innovative approaches to dementia

POS4. Posters - Innovation in care and research

POS4-55Effects of a multimodal exercise protocol using assistive technology on cognitive, psychological and functional status of patients with Neurodegenerative Diseases

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The aging process is associated with progressive loss of physiological, psychological and cognitive functions that lead to inevitable disabilities which contribute to functional dependence and consequently in loss of quality of life (QoL). In this sense, changes in cognitive abilities contribute to the increased incidence of Neurodegenerative Diseases (ND). Furthermore, it is known that all health-related components of physical fitness seem to be compromised in these individuals. In addition, there is evidence of the benefits of physical activity using assistive technology on functioning, cognition, psychology and QoL in older adults-patients with ND. Aim of this study was to investigate the effects of a multimodal exercise intervention using a therapeutic protocol combining aerobic and anaerobic exercise with resistance training using THERA–Trainer rehabilitation equipment on functional outcomes, cognitive performance, and QoL, among individuals with ND. Method: 27 participants with ND (moderate dementia (n=3), Alzheimer's disease (n=3), Parkinson disease (n=5), Multiple Sclerosis (n=14), and other ND (n=2), mean age 59.15 years included in this experimental study. A 60 minutes multimodal therapeutic exercise protocol was applied, twice a week for 20 weeks. Participants were assessed before and after the intervention using the following instruments: Body Mass Index, Body Surface Area, Mini Mental State Examination, Senior Fitness Test, Activity-Specific Balance Confidence, Timed 25-Foot Walk Test, Berg Balance Scale Greek, Fatigue Severity Scale, Expanded Disability Status Scale, EuroQol, Short-Form Health Survey physical and mental health, Hospitality Anxiety and Depression Scale, Multiple Sclerosis QoL-54. Our study showed that a 20-week multimodal physical activity program using assistive technology is an important strategy for attenuating and/or improving functional status and QoL decline and promoting cognitive improvement in patients with ND. These findings support the importance of implementing multimodal physical activity programs for this population. Study Limitations are: short intervention time and small sample size of patients with each disease.

Inclusion and intersectionality - Minority ethnic groups

POS5. Posters - Inclusion and intersectionality

POS5-01Dementia risk factors and brain health: a scoping review of interventions to reduce social isolation and loneliness among minority ethnic populations in OECD countries

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Introduction: Dementia is predicted to affect around 139 million people globally by 2051, with a seven-fold increase forecasted for minority ethnic populations in the UK compared with a two-fold increase in White British communities. Social isolation or loneliness is one of the 12 modifiable risk factors that can be targeted to reduce dementia risks. However, social isolation and loneliness are often under-recognised public health problems in minority ethnic communities, and the dimension of change crucial for reducing them as part of dementia risk prevention in the communities is unknown. We conducted a scoping review to identify interventions addressing social isolation and loneliness designed for minority ethnic communities. We examined the mechanisms of action that linked interventions to dementia prevention and the culturally sensitive approaches adopted.
Methods: We searched Medline, CINAHL, Psych Infor, Web of Science, Scopus, and the Psychology and Behavioural Sciences Collection and screened the data using Covidence. At every stage, at least two reviewers independently reviewed 10% of the results, and the inter-reviewer agreement was checked.
Results: A database search (31.11.2023) found 6729 after deduplication, but only 12 studies met inclusion criteria. Studies were categorised into four intervention types, including social facilitation, befriending, Leisure and skill development, and health education; seven studies explicitly targeted minority ethnic populations. Interventions that focused on community building, social interaction, and support through social facilitation activities and used culturally sensitive strategies relevant to participants' ethnic and religious culture were reported to be most effective in reducing social isolation and loneliness. However, the theoretical connection between intervention mechanisms and dementia prevention was not clear. Moreover, the varied outcomes, measures, and methods pose a generalisation challenge.
Conclusion: Interventions aimed at addressing social isolation and loneliness among minority ethnic communities in OECD countries have not been tailored alongside dementia risk as part of dementia prevention efforts.

Inclusion and intersectionality - Minority ethnic groups

POS5. Posters - Inclusion and intersectionality

POS5-02Barriers and facilitators to recruitment and retention of underrepresented groups in dementia prevention research: a scoping review

Awaale Fuad Rirash
Erasmus MC

Background: Dementia prevention studies in the Netherlands have predominantly targeted affluent native Dutch. This is problematic, since underrepresented populations, often characterized by migration backgrounds, low socioeconomic status, and low health literacy, face an increased risk of developing dementia. We need more insight into factors that hinder and/or support inclusive prevention research. We aimed to review the literature to explore country-specific barriers and facilitators for recruiting and retaining underrepresented populations in dementia prevention research.
Objective: The study objective is to conduct a (systematic) scoping review of published literature on Alzheimer's disease and related dementia's (ADRD) research recruitment and retention among (healthy) underrepresented high risk groups, to identify gaps and priorities to inform future prevention research and action plans in the Netherlands. This research is part of the NDPI.
Methods: A scoping review was conducted following the PRISMA-ScR protocol. Comprehensive searches using keywords like 'ethnic' and 'dementia' were conducted in Medline, Embase, WoS Core Collection, CINAHL, and Cochrane Library, without restrictions. Articles were screened at title and abstract level and at full text by two independent reviewers, using Covidence. Conflicts were resolved through consensus.
Results: The search resulted in 1955 unique articles, 1674 were removed during title/abstract screening. From 186 full-text screened articles, 66 were selected for data extraction, including 46 dementia prevention trials and 20 reviews focusing on recruitment/retention in ADRD research. Preliminary synthesis of data suggests common barriers and facilitators across various domains, including mistrust, key persons/organizations, logistics, awareness, stigma, altruism, and continued communication, with most data originating from the U.S.
Discussion: This scoping review provides an overview of relevant barriers and facilitators for recruiting and retaining a cognitively healthy diverse study population in the context of dementia prevention research. Understanding and addressing these factors are essential for developing effective prevention strategies tailored to diverse populations and improving health equity.

Inclusion and intersectionality - Minority ethnic groups

POS5. Posters - Inclusion and intersectionality

POS5-03Disparities in dementia diagnosis rates in ethnic groups: analysis of primary care data in Bradford, UK

Lin Gong, Kate Best, Andrew Clegg, Magda Jordão

Introduction: Existing studies examine dementia rates in broad ethnic groups such as black and Asian, which may mask important disparities in dementia diagnosis rates in specific ethnic sub-groups.
Materials and Methods: CBradford consists of routinely recorded primary care data from 800,000 residents of the Bradford region. This study includes 289,218 patients aged 45 and over between 2009 and 2019 from CBradford. We estimated the dementia incidence overall and by ethnic group: white British, African, Caribbean, south Asian, east Asian, mixed, other white, and other ethnic group. We further estimated incidence rate ratios adjusted for age and sex using Poisson regression.
Results: A total of 58,065 people developed dementia, including 39,477 white British (68.0%), 7,262 south Asian (12.5%), 1,422 other white (2.4%), 330 Caribbean (0.6%), 328 east Asian (0.6%), 514 mixed (0.9%), 200 other ethnic group (0.3%), and 94 African (0.2%), with a missing rate of 14.5%. The overall incidence rate was 17.9 per 1,000 person-years at risk. Our results suggest that compared with the white ethnic group, the incidence was 35% higher in south Asian (IRR 1.35, 95% CI 1.32–1.38) and 4% higher in black Caribbean (IRR 1.04, 95% CI 0.93–1.16). Conversely, the incidence of dementia diagnosis was 33% lower among east Asian (IRR 0.67, 95% CI 0.60–0.74) and 61% lower among black African (IRR 0.39, 95% CI 0.32–0.48).
Conclusion: This study is among the first to report the incidence of dementia diagnosis across eight ethnic groups in the UK. Our findings highlight the ethnic disparities in dementia diagnosis and draw policy attention to the causes and impact of this inequality.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-05The OASIS Protocol: a novel co-adaptation and co-evaluation of the coping strategy enhancement intervention for hallucinations in the context of dementia

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Background: Historically, anti-psychotic medication has been the first line of treatment to support people living with dementia (PLWD) who experience hallucinations, which has shown to have negative side effects, such as stroke. Currently, no non-pharmacological interventions exist that aim to support PLWD and their carers with the distress associated with hallucinations. While patient and public involvement (PPI) in dementia research is prevalent, it is lacking in the area specifically focused on hallucinations. Therefore, the OASIS study aims to fill this research and treatment gap and involve PLWD and their carers in co-adapting and co-evaluating a psychological intervention for hallucinations.
Method: This study will comprise of four phases:
Phase 1 involves focus groups with PLWD, their family carers, and clinicians to co-adapt the Coping Strategy Enhancement (CSE) intervention. Phase 2 will evaluate the adapted intervention in a single-arm feasibility trial in community settings with PLWD and their carers. This phase will occur across two sites in the UK and the adapted CSE intervention will be delivered by clinical psychologists. In Phase 3, quantitative and qualitative data will be collected from participants to assess feasibility outcomes. Phase 4 will revisit the focus groups from phase 1 to co-evaluate the study consider next steps for the CSE intervention.
Findings: The protocol for the OASIS study will be presented, including the work that has led up to its development from a lived experience advisory panel and highlighting collaboration with PPI groups in Phases 1 and 4. Intended and anticipated outcomes of the novel therapeutic adaptation will be discussed.
Conclusion: The OASIS study represents a critical step forward in addressing the distressing phenomenon of hallucinations in PLWD and their carers. By prioritising PPI in the development and evaluation of a non-pharmacological intervention, this research aims to fill a significant gap in dementia care and research.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-06Celebrating patient and public involvement groups for people with dementia in Scotland: NRS Neuroprogressive and dementia network and ENRICH Scotland

Rosalie Ashworth[1], Kirsty Hynes[2]
[1]NRS Neuroprogressive and Dementia Network, [2]

NRS Neuroprogressive and Dementia Network and ENRICH Scotland would like to present a joint poster which highlights the work of the patient and public involvement groups, Partners in Research and RICH Voices. The poster celebrates the successes of the group, and offers insights into patient and public involvement work for people living with dementia in the community and care home settings. Our poster also poses questions about how to reach underserved groups, and how to make sure that we offer a range of opportunities whilst acknowledging the challenges of appropriate funding, time, and support. We will share the progress of ongoing activities including co-research opportunities and our accessible research platform, which seeks to improve access to accurate, accessible information about research into dementia, aging, care, and neuroprogressive disease.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-07Working together: co-creating research to understand what helped people living with dementia during the Covid-19 lockdowns

Louise Ritchie[1], Elaine Deehan[2], Marion Ritchie[2], Debbie Tolson[1], Anna Jack-Waugh[1], Tony and Angela Worthington[3], Margaret and Barry Northedge[4], Elaine and Ian Symington[5], Euan Petrie[3], Rachel Allen[1], Connor McDonald[1], Wendy Rankin-Smith[6]
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Involving people with lived experience in research or as members of research teams is considered good practice. Indeed, Scotland's Brain Health and Dementia Strategy says 'we are all researchers'. It implies that some of the best research questions and most useful studies come from working together. This is why the academic team from the Alzheimer Scotland Centre for Policy and Practice (ASCPP) have worked closely with the members of the Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN) for several years. Discussing research during the COVID –19 pandemic

was a useful way to keep connected. During one of these conversations, members of the NDCAN research group voiced frustration at the negative messages and focus of research around COVID-19 and dementia. What could we learn about supporting people with dementia from lockdown experiences-anything? From there, an idea was born, if no-one was doing this then we would do it ourselves! Extending an invitation to the SDWG, we developed an inclusive research team to carry out a research project that aimed to identify the things that helped people living with dementia and family most in relation to life with dementia during the pandemic. The research team consisted of fourteen members, including seven individuals with lived experience, five academics, and two research students. Each team member actively contributed to the study's design and planning, and then specific roles and responsibilities were shared to support delivery of the project. Using Nominal Group Technique (NGT) as our method, we recruited 19 people to participate in two NGT group discussions. This poster will present insights gained from working as an inclusive team and present findings emphasising the significance of maintaining social connections. The study reveals how online groups provided structure and social support during the pandemic, shedding light on effective coping mechanisms.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-08Involvement of family caregivers in dementia care research: a scoping review

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Background: Family caregivers of people with dementia experience burdensome care situations at home. Involving them in research is crucial to better address their specific needs and to optimize the design and conduct of studies. We aimed to investigate how (far) family caregivers of people with dementia are involved in dementia care research.
Methods: We conducted a scoping review of studies reporting on the active involvement of family caregivers of people with dementia in the planning and conduct of research. We searched MEDLINE, CINAHL, Scopus, PsycInfo (June 2023), reference lists of included studies, and pertinent evidence syntheses (September 2023) and we contacted experts to

identify additional studies (December 2023). One reviewer screened references with confirmation of a second reviewer, if necessary. Data was extracted using a predesigned data extraction sheet comprising elements of the Guidance for Reporting Involvement of Patients and the Public (GRIPP2) checklist.
Results: We included forty studies. Thirty studies were published since 2018 and had a qualitative design. Twenty studies were conducted in the context of development of social and/or digital interventions. Thirty-seven studies described family caregivers' involvement in the execution phase of the study; six studies described involvement in the preparatory and eight studies in the translational phase. In thirty-two studies family caregivers adopted a role of a co-thinker, in nine studies the role of a partner and in one study the role of a decision-maker. Eight studies reported barriers and facilitators of research involvement and fourteen studies reported on impact of family caregivers' involvement.
Conclusion: The involvement of family caregivers in research appears in different forms; however, a more balanced involvement across all project phases and roles is desirable. More research into barriers, facilitators and facilitative strategies is needed and a wider reporting of formalized methods for recording meaningful impact would be helpful.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-09France Alzheimer's working group of people living with dementia

Kevin Rabiant
France Alzheimer

In early 2024, France Alzheimer et maladies apparentées created a working group of people living with dementia and one of their caregivers in order to take into account their needs and their feedback regarding innovatives solutions, mostly focused on new technologies, with or without AI.
This working group is formed by ten couple composed of one person with dementia and one of their care partners. Each one of them is involved in the discussion regarding the evaluated solutions. The main goal of that task force is to give voices directly to the people concerned by these solutions and to empowered them with a decision making process that will lead to significative actions.
To this end, France Alzheimer endows a specific power to the group that allows it to accord a communication partnership between the creator of the solution deemed interesting and the

association.
Moreover, this working group will be consulted regarding different communication campaigns held by professionals in order to insure that people living with dementia and their loved ones are able to fully understand it and take decision based on such knowledge. This will be used, for instance, with medical communication supports regarding innovative therapeutics that should be available in a near futur.
This group will meet 5 times a year using videoconference and should be able to evaluate up to nine solutions each year. Their missions could evolve based on the implication of each member to tackle research related issues, such as research protocole reviewing or research interview participation. The first meeting is expected in early June and the first solutions will be evaluated in Septembre 2024.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-10Co-producing a core outcome set for social prescribing interventions for people living with dementia and their carers

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The importance of including the perspectives of relevant patient and public involvement in the development of core outcome sets (COS) is becoming better recognised. Lack of consensus of core outcomes is evident from the current literature assessing social prescribing for people living with dementia (PLWD) and their carers, as is the involvement of PLWD and carers in the development process.
Consequently, in order to develop a COS for social prescribing interventions for PLWD and their carers a collaborative co-production method was taken. PLWD and carers were consulted at all stages of development, with initial co-design focus groups developing the research method to be that of an iterative modified delphi approach, that consulted with PLWD and carers at all stages.
To start the process, focus groups were conducted with PLWD and carers to develop which outcomes might be of importance, developing a large set of suggested domains and outcome items. These were then collated and brought back to focus groups of PLWD and carers to

confirm and prioritise. A search of existing COS for similar interventions was conducted, and the findings from focus groups and literature collated and prioritised by key stakeholders in research and social prescribing provision. A reduced and refined list of COS was taken back to focus groups of PLWD and carers in order to finalise and gain consensus. The importance of including PLWD and carers in the co-production of interventions and COS is being increasingly acknowledged. This process demonstrates a methodological approach where PLWD and carers can play a part in each step of a COS process ensuring a meaningful and representative evaluation.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-11Scottish Dementia Working Group and National Dementia Carers Action Network – lived experience partners in research

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[1]Alzheimer Scotland, [2]Scottish Dementia Working Group

The Scottish Dementia Working Group (SDWG) and National Dementia Carers Action Network (NDCAN) are proud partners in research, supporting purposeful dementia related research by bringing their personal experiences to help shape and inform the aims and objectives of research projects; volunteering as research participants; and being kept informed of activity within the dementia research world.
Both Groups have established sub-groups of members with a particular interest in research, to drive forward their research priorities. Working with key partners to deliver meaningful and purposeful dementia research, whether as co-producers, participants, consultees, or recipients of research information.
Through this work, members have established strong relationships with a wide range of dementia research partners, including with the Centre for Discovery Brain Sciences at Edinburgh University, meeting with its deputy-director Professor Tara Spires-Jones and students to discuss their work and touring the facility to see, first-hand, the research that is taking place there.
The Groups have used their research partnerships to publicise the excellent work of these facilities and to keep research in the public eye. They have produced eye-catching newsletters to share their experiences to a wider audience, using quotes from members involved in visiting the facilities to bring to life the exciting work going on:

"We learned about using live brain tissue from post operative patients, incubating it and nourishing it to survive for 28 days. Allowing scientists to view the live electrical and chemical exchanges on specialist equipment."
"We learned about the life cycle of fruit flies and how this aids learning on diseases such as Alzheimer's. Dissecting the brain of a fruit fly is mind blowing!"
Working as lived experience partners in dementia research can only benefit us all for the future, encouraging greater awareness of and participation in dementia research.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-12Meaningful patient and public engagement in dissemination – embedding co-production in dementia research

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Background: Awareness and education are some of the top research priorities for stakeholders in dementia research. Patient and public involvement groups across Europe agree on analytical steps and interpretation of data to support the message from research output better. To inform the public about a new person-centred tool to identify the symptoms and needs of people with dementia in the community, we asked our diverse PPI group in Switzerland how best to disseminate our findings.
Methods: A participatory workshop was conducted in a hybrid format. All participants were sent a file, including a video of a presentation about study results and corresponding questions about the style, understandability, and choice of journal/conferences to prepare for the workshop in advance.

Results: We ran our first workshop with 22 participants, including one person with dementia, informal carers, nurses, charity leaders, journalists and editors took part (15 in person and seven online). We gained insight into how to disseminate important but complex results meaningfully to different audiences. Three essential components when planning dissemination to different audiences (e.g. politicians, informal carers, health care professionals) outside academia must be considered: It was recommended to use 1) illustration (including graphs) but with minimal colour variation and simple explanation of icons; 2) different language formats to address and reach different audiences, support from non-academic writers is helpful; 3) thinking and developing the main message together because it needs to demonstrate implications for practice.
Conclusion: Raising awareness and educating the public and policymakers about the needs of people with dementia living at home relies on a well-thought-through dissemination strategy. Leaving PPIs in the lead to develop a compelling dissemination strategy will increase their chances of being heard.

Inclusion and intersectionality - Public involvement in dementia research

POS5. Posters - Inclusion and intersectionality

POS5-13INnovaTions in divERsity and Equity in social health research in DemenTia: The INTEREST Working Group

Louise Hopper[1], Marjolein de Vugt[2], Martina Roes[3], Sara Barthels[4], Dympna Casey[5], Adelina Comas[6], Ana Diaz[7], Rose-Marie Dröes[8], Clarissa Giebel[9], Wei Qi Koh[10], David Neal[8], on behalf of the JPND INTEREST Working Group[11]
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Alzheimer's Disease and related disorders (ADRD) pose significant global health, societal, and economic challenges. With dementia cases projected to double by 2040, urgent action is needed to address the increasing impact on individuals, caregivers, and communities. A shrinking caregiving workforce amplifies this societal concern. Despite advancements,

substantial unmet needs persist due to intertwined challenges.
Individual characteristics, geographical, socioeconomic, ethnic, gender, and educational disparities, hinder access to and utilization of care services for individuals and caregivers leading to inequities in dementia care and research. Prevailing interventions are often generic, neglecting individual differences and resulting in limited effectiveness. Furthermore, promising dementia support technologies face hurdles such as ethical concerns, insufficient user involvement and high costs, hampering their full realization. The implementation gap exacerbates these challenges by impeding the integration of evidence-based models and interventions into routine care practices. Barriers such as time constraints, inadequate training and lack of policy hinder the widespread adoption of effective care practices. Bridging this gap necessitates innovative approaches to evaluate and integrate existing and emerging dementia care practices.
The JPND-funded INTEREST (INnovaTions in divERsity and Equity in Social health research in DemenTia) working group proposes a comprehensive, multi-level approach. By harnessing international and interdisciplinary expertise, INTEREST will address health care disparities and inequities in dementia care and research, enhance intervention tailoring, and bridge the implementation gap. Grounded in principles of social health and intersectionality, INTEREST will identify unmet needs, evaluate resources, and result in strategies for improving dementia care: (i) strategic policy and best practice guidelines; (ii) research frameworks and methodologies for transdisciplinary research for diverse groups of people with dementia; (iii) build research capacity. Collaboration with the European Working Groups for People with Dementia and for dementia carers ensures the inclusion of perspectives and experiences of individuals living with dementia, fostering inclusive and participatory research practices.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-14Enabling work for people with dementia - recommendations for Interventions: a mixed-methods review

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Background: Worldwide, 50 million people are living with dementia. With an aging workforce and increasing statutory retirement age, more people will develop dementia while still employed. Interventions aimed at retaining employment, can mitigate and delay cognitive decline associated with dementia. Understanding the various factors (e.g., social and societal) influencing work interventions for people with dementia is crucial to support their continued or resumed employment and how these are perceived by stakeholders.
Aim: This review investigated recommendations for work interventions for people with dementia, from the perspective of people with dementia, relatives, employers, and co-workers.
Method: The review employed a mixed-method approach, incorporating 15 original studies conducted across seven countries and published between 1989 and 2023. The total sample size comprised 630 participants, including 122 people with dementia, 14 relatives, and 494 professionals, respectively.
Results: Findings indicate that it is possible to live and work well with dementia, if collaborative solutions are continuously negotiated to meet the needs of the person with dementia as well as the workplace, and with attention to possible contextual enablers and barriers. The reviewed studies present diverse approaches to work interventions for people with dementia, including adapted and supervised work settings, community-based buddy programs, and interventions involving people with dementia as peer support or educators. The review highlights five key elements crucial for effective work interventions for people with dementia: Collaboration, Meaningfulness, Contextual relevance, Knowledge-based and Dynamic approaches.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-15Comparing pre-diagnostic symptoms of young-onset dementia and late-onset dementia in the general practice

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Maastricht University

Background: The typical perception of dementia involves an elderly individual experiencing memory problems, characteristic of late-onset dementia (LOD). Conversely, young-onset dementia (YOD) manifests before age 65, frequently impacting individuals still engaged in various active roles. YOD is caused by a large heterogeneity of subtypes, resulting in very diverse symptoms with often an insidious onset, posing challenges for general practitioners to recognise YOD. Diagnosis of YOD is 4.4 years on average, compared to 2.8 years in LOD. This study aims to identify the difference in pre-diagnostic symptoms between persons with YOD and persons with LOD at the general practice (GP), to achieve earlier recognition and diagnosis of YOD, essential to receive adequate support.
Methods: This case-control study used GP-written patient files of 88 cases with YOD and 174 controls with LOD from the Research Network Family Medicine database. Cases and controls were matched on gender and GP-practice. Symptoms up to five years prior to diagnosis were gathered from GP patient files and clustered into eight different symptom categories, namely cognitive symptoms, affective symptoms, behavioural symptoms, vascular symptoms, gait disturbances, changes in weight or appetite, social symptoms, and disturbances in daily functioning. Differences in symptom category presence were analysed for each year during five years prior to diagnosis (y) separately using binary logistic regression.
Results: The analyses showed that affective (2y, 1y) and social symptoms (5y, 4y, 1y) were more common in persons with YOD, and gait disturbances (4y, 2y) were less common compared to persons with LOD.
Conclusion: Persons with YOD present differently from persons with LOD at the GP up to five years prior to diagnosis, in multiple symptom categories. These findings offer new insights into pre-diagnostic YOD, aiding in timely recognition. Further research with larger sample sizes is recommended to investigate these findings more comprehensively.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-16Developing a practical toolkit to support continued employment in young-onset dementia using participatory action research

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Background: Young-onset dementia (YOD) often results in significant loss, including amongst others employment loss. In persons with YOD, employment loss can threaten mental and physical well-being, as well as social inclusion. This study aims to develop a practical toolkit (WorkDEM Compass) via participatory action research (PAR). It supports employees with YOD, by aiding them and other relevant stakeholders in continuing employment for as long as possible.
Methods: To develop this practical toolkit, we conducted two co-creation sessions, based on scientifically proven methods. Participants consisted of employees with YOD, relatives of employees with YOD, employers and HR-professionals, occupational physicians, and dementia care professionals. The aim of these sessions was to provide concrete substance to the content and structure of the WorkDEM Compass, tailored to each target group. This data provides the input for further development of the support tool.
Results: Preliminary results show that there is a demand for knowledge and awareness about YOD, and practical tools to guide several stakeholders in the employment process. The preference lies particularly with a website providing information for all involved target groups. Additionally, each target group has specific needs. For instance, occupational physicians require guidelines on detecting YOD in the workplace context. Similarly, employers express the need for knowledge on identifying YOD and supporting an employee within their own work environment. Furthermore, collaboration among various target groups to coordinate efforts is crucial.
Conclusion: There is a clear demand for knowledge and tools to support employees with YOD in the workplace. Stakeholders prefer a comprehensive website, but specific needs vary. These findings form the building blocks of the WorkDEM Compass, which we are currently developing. By co-developing the toolkit with end users, we may improve implementation uptake and enhance the possibility to maintain meaningful occupations, ultimately fostering a supportive and inclusive work environment.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-17Needs of persons with young-onset dementia and their informal caregivers, explored by dementia subtype, phase in the disease process, and living setting: a scoping review

Maud Ritzen[1], Kirsten Peetoom[1], Sara Laureen Bartels[1], Christian Bakker[2], Marjolein de Vugt[1]
[1]Maastricht University, [2]Radboudumc

Background: Young-onset dementia (YOD) occurs before age 65, often during an active, pre-retirement life phase and encompasses a wide range of causes and symptoms. Persons with YOD and their informal caregivers are faced with unique and complex needs, highlighting the crucial role of psychosocial support. However, research has shown that psychosocial support often fails to optimally meet the needs of persons with YOD and their informal caregivers, as this support is commonly developed for late-onset dementia. Therefore, the present review aims at providing a comprehensive overview of needs of persons with YOD and their informal caregivers.
Methods: This study is part of the Dutch YOD-INCLUDED consortium. Literature for this scoping review was systematically searched in PubMed, APA PsycINFO, CINAHL, and Embase. Needs of persons with YOD and their informal caregivers were extracted by a combination of inductive and deductive coding, and specified by dementia subtype, phase in the disease process (before diagnosis, shortly after diagnosis, and long-term), and living setting (living at home or in other (care)settings).
Results: The search identified n=2.715 unique articles, of which n=130 articles were included. Preliminary findings from the analysis of n=42 articles indicate that persons with YOD need emotional and social support, independence, meaningful engagement, and adequate YOD day-care. Informal caregivers, including spouses, siblings, and children, commonly need knowledge about YOD, emotional and social support, validation, respite care, and self-care. Additionally, it is aimed to explore potential variations in needs based on YOD subtype, phase in the disease process, and living setting. Final results are expected by autumn 2024.
Conclusion: This scoping review will provide a detailed overview of the unique and complex YOD needs. This overview can serve as foundation for the (further) development of psychosocial support that meets the needs of persons with YOD and their caregivers.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-18The predictive value of social cognition assessment over and above neuroimaging for 1-year functional outcomes in behavioral variant frontotemporal dementia

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Aim: Behavioral variant frontotemporal dementia (bvFTD) is characterized by prominent socioemotional deficits that negatively impact various aspects of daily living. This study aims to identify the socioemotional predictors of functional status at 1-year follow-up and examine whether socioemotional assessment provides additional predictive value for clinical outcomes beyond neuroimaging data among individuals with bvFTD.
Methods: A total of 78 patients with bvFTD were assessed at baseline with a comprehensive battery of socioemotional functioning involving face-to-face tests and informant-based measures. Regression modeling was performed to identify the strongest socioemotional predictors of functional outcomes (Functional Activities Questionnaire, FAQ) at 1-year-follow-up. In a subset of 57 patients with available baseline structural magnetic resonance imaging (MRI) data, the volumes of functional networks particularly vulnerable in bvFTD, including the semantic-appraisal network, salience network, default-mode network, and frontoparietal network, were obtained by summing regions of interest derived from voxel-based morphometry of atrophy. Multilevel regressions were performed to compare the predictive value of social cognition measures above 1) demographics/severity and 2) neuroimaging data.
Results: Neuropsychological tests assessing social perspective taking and social norm knowledge appeared to be the most robust socioemotional predictors of FAQ at the 1-year-follow-up assessment ($p<0.05$). Structural MRI data alone accounted for 29.02% of the variance in FAQ outcome, but increased to 47.88% when social cognition measures were included in the model.
Discussion: This study highlights the significant contribution of quantifying social cognition, particularly theory of mind and social semantics, in order to predict which bvFTD patients will quickly develop adverse functional outcomes. Socioemotional assessment can capture unique aspects of disease progression and functional decline not fully captured by structural MRI alone.
Conclusions: The integration of socioemotional assessments in clinical practice with bvFTD can significantly enhance clinicians' prognostic accuracy for functional outcomes, thus informing refined treatment strategies for these individuals.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-19The meanings and experiences of gratitude for people living with young-onset dementia

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Background: Gratitude is a character strength with one of the strongest predictors of life satisfaction. Gratitude can strengthen relationships, correlates with health-related quality of life and has been found to be meaningful for older people living with dementia. The age and life stage that someone develops symptoms of dementia is one difference that impacts how people relate to and experience dementia. Young-onset dementia (YOD) refers to when people develop symptoms of dementia before the age of 65, and gratitude has emerged serendipitously in YOD research in the context of coping. As people with YOD have expressed an unmet need for tailored support and services, exploring factors that may contribute to people with YOD's wellbeing, such as gratitude, is important. This study therefore aimed to explore the meanings and experiences of gratitude for people living with YOD.
Methods: Nine people living with YOD each took part in a semi-structured interview, that had been developed with input from a patient and public involvement group. This was a qualitative study, using Interpretative Phenomenological Analysis to embody an exploratory approach.
Findings: Two superordinate themes and six subthemes were developed to capture how participants cultivated and experienced gratitude, as mechanisms for living well. 'Gratitude as a cultivated approach to life' included: 'Acknowledging the challenges', 'Slowing down allows me to savour the moment', and 'Choosing a grateful mindset'. 'Interpersonal gratitude' included: 'Feeling part of something bigger', 'Feeling seen and supported', and 'Sharing the thank-yous'.
Conclusions: This study demonstrated that gratitude was a meaningful concept for people living with YOD and had a role in fostering well-being. Cultivating gratitude often involved an active choice, and was connected to life changes and challenges experienced since developing YOD. Experiences of gratitude were largely interpersonal, with felt and expressed gratitude for relationships and communities, highlighting the importance of social support.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-21iSupport for young people: a multi-country collaboration to increase identification and support available to young people who live in families affected by dementia

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Young people that live in families affected by dementia often have some level of caring responsibilities. As young dementia carers (YDCs) they rarely receive appropriate training and support. Their visibility and identification is dangerously low, in part due to low level of self-recognition and a lack of awareness amongst relevant support services about this cohort and their needs. In response to this, iSupport for Young People was developed; the first online tool of its kind, providing training and support to this group so they can understand dementia, how it can affect their family member and what changes are expected.
The aim of this international exploratory study was to use iSupport for Young People as a starting point to generate discussions on how to increase the awareness and support available to this vulnerable group in the UK, Spain, Italy, and Brazil. To date, we have completed: 1. The translation of iSupport for Young People and the promotional short film into Spanish, Portuguese and Italian; 2. We have also produced a free short online course (in English) with information and guidance for professionals and families on iSupport for Young People and how to use it to best support YDCs. We are currently in the process of disseminating these outputs and carrying out stakeholder showcase events in each of the countries. These events will collate relevant information on the contextual factors to consider when adapting and tailoring iSupport for Young People to each country's individual implementation context. Our study will produce evidence to inform future research work to continue to raise awareness and develop 'fit for purpose' support initiatives for YDCs in the UK, Spain, Italy, and Brazil.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-22Connected care: building bridges between the (semi)residential care and home care in emotional stress and sleep management in young onset dementia

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Background: People with young onset dementia often prefer to reside in their own home setting until it remains no longer possible for them or their relatives. As the course of YOD progresses, both individuals with YOD as well as their relatives often face emotional distress which can go hand in hand with poor sleep and a decrease in wellbeing for both parties. Caregivers in the home care for individuals with young onset dementia (YOD) are therefore often challenged in handling emotional stress and sleep problems as these symptoms regularly occur in individuals with YOD. Care organisations in the (semi)residential setting can play a role to help the caregivers in the home setting with these challenges. This project aims to build bridges between competences in (semi)residential care in coping with emotional distress and healthy sleep management in individuals with YOD.
Methods: In total, a consortium of 12 formal care organisations of which semi-residential (n=6) and residential care (n=6) are receiving information regarding emotional stress and healthy sleep management in YOD. In a further stage, both formal home care organisations (n=4), informal caregivers (n=10) and people with YOD (n=10) will be assessed for existing needs in terms of emotional distress and healthy sleep management. Based on group interviews, a training package will be developed and delivered.
Results and conclusions: Based on the needs assessment in home care providers for YOD with regard to emotional stress and healthy sleep management as well as the gap analysis on available competences in the (semi)residential care setting, a framework 'connected care' will be developed. In order to transfer knowledge and skills in handling emotional stress and healthy sleep management between actors in different settings, an e-learning will be developed and made available for both (semi)residential and home care organisations for YOD.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-23Distinguishing pre-diagnostic young onset dementia and depression symptoms in the general practice

Stevie Hendriks, Meagan Hannemann, Charles David, Huibert Tange, Sebastian Köhler, Marjolein De Vugt
Maastricht University

Background: Young-onset dementia (YOD) has many underlying etiologies, resulting in a large heterogeneity of first symptoms. This makes it difficult for General Practitioners (GPs) to recognize YOD and prolongs the time from symptom onset to diagnosis. Persons with YOD are often first misdiagnosed with depression, due to the overlapping early symptoms. Distinguishing YOD from depression is necessary to avoid this misdiagnosis and prolonged time to diagnosis. Therefore, this study aimed to identify differences in early symptoms between persons with YOD and persons with depression in the pre-diagnostic phase.
Method: This study is part of the Dutch national YOD-INCLUDED consortium. A case-control study nested in a primary-care registry was performed. 129 persons with YOD were included. For this study, persons with YOD were defined as having a diagnosis before the age of 70 years, to account for a possible diagnostic delay. The cases were matched with 129 age- and sex-matched controls who were diagnosed with depression. Symptoms reported in the GP office up to five years before diagnosis were compared between the two groups. Symptoms were extracted from written GP notes, categorized in domains, and analyzed using binary logistic regression.
Result: Results are expected in July. We hypothesize that there will be a difference in symptom categories present in the years before diagnosis between persons with YOD and persons with depression. Specifically, we expect differences in cognitive, affective, behavioral, and social symptoms. We expect a difference in affective symptoms, with persons with YOD having more apathy, whereas persons with depression have more depressive and anxiety symptoms.
Conclusion: Expected results of this study may help the GP to differentiate between presenting symptoms of YOD and depression. This could lead to earlier recognition of YOD in general practice, resulting in earlier referral of young persons to the memory clinic.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-24Post-diagnostic care and support for people with young-onset dementia: a Dutch national survey on use and experiences

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Objective: People with young-onset dementia (YOD) and their family members have distinct needs due to symptoms arising in earlier life stages and a more diverse clinical presentation, compared to people with late-onset dementia. Since dementia care is mostly tailored to preferences of older people, people with YOD and family members experience a lack of fit between their needs and available services. With a growing number of 3.9 million people living with YOD worldwide, improving care and support for them is extremely important. Our aim is to identify the use of and experiences with specific types of services after receiving a dementia diagnosis, in a wide range of people with YOD and their supporters. This includes people of various ethnical backgrounds and with different subtypes and stages of dementia.
Methods: In co-creation with end-users, we developed a survey with closed and open-ended questions on the use of YOD-related care and support, and their experiences with these services. Additional questions focus on dementia-related information (such as dementia subtype, severity, and time since diagnosis), and demographic data (such as ethnicity, religion and socioeconomic status). In order to obtain both perspectives, people with YOD and supporters received separate questionnaires. The design is based on a survey held in the United Kingdom as part of the Angela Project. Recruitment for the survey takes places via the overarching, national young-onset dementia cohort (YOD-cohort), which is part of YOD-INCLUDED and ensures good exposure throughout the country.
Results: The survey has been open for participation since March 2024. Preliminary results will be presented at the Conference. We aim for a total sample size of 250 respondents.
Conclusion: This study provides us with insight on age- and needs-appropriate care and support, helping us to create an inclusive and personalized healthcare system for people with YOD and their supporters.

Inclusion and intersectionality - Young onset dementia

POS5. Posters - Inclusion and intersectionality

POS5-25The pre-diagnostic phase of young-onset dementia: a scoping review

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Background: Dementia before the age of 65 is called young-onset dementia (YOD) and affects about 3.9 million people worldwide. Heterogeneity in underlying etiologies lead to clinical variability of first symptoms, which can include cognitive decline, behavioral changes, and language impairment. Younger onset age and prevalence of non-cognitive symptoms poses challenges in recognizing YOD by clinicians, leading to a diagnostic delay of 4-5 years. Recognizing prodromal symptoms is vital for early YOD diagnosis, facilitating access to appropriate services and informal care arrangements. We aim to gain insights into the pre-diagnostic phase of YOD by exploring available literature on presenting symptoms and factors aiding timely diagnosis.
Method: Literature search was done across PubMed, Embase, Web of Science, and PsychInfo. Two independent reviewers screened 4,403 titles/abstracts, followed by a full-text review of 556 articles. Standardized data extraction included time to diagnosis, prodromal symptoms, barriers, and facilitators to diagnosis amongst others. Review reporting adheres to PRISMA-ScR guidelines.
Results: We included 266 studies of which time to diagnosis was mentioned in 45 studies and ranged from 1 to 15 years. We categorized early symptoms into cognitive, affective, behavioral, vascular, gait, changes in weight or appetite, social and symptoms affecting daily functioning. Prevailing early symptoms reported in 103 studies, were forgetfulness, apathy, depression, learning difficulties, problems with speech, mistakes at work and self-neglect. Common barriers to timely YOD diagnosis included nescience about YOD among clinicians, people with YOD and their caregivers, misdiagnosis, misattribution, and denial while facilitators for early diagnosis were YOD dedicated diagnostic services, timely referrals, and persistence of follow up in the diagnostic process.
Conclusion: This review shows diversity of first symptoms of YOD and identified several barriers and facilitators for timely diagnosing YOD. This information can be used in future research and clinical practice to improve the diagnostic trajectory for people with YOD.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-01Grief, loss, and bereavement in dementia – what does the research say about psychosocial interventions?

Amy Pepper, Karen Harrison-Dening
Dementia UK

Anticipatory or 'pre-death' grief as experienced by carers of people with dementia is a well-established phenomenon in the research literature, with much written about the identification, impact and interventions. However, much less is known about how grief might be experienced by people with dementia themselves. Grief can also be experienced by people with dementia, with some evidence showing that they may also experience anticipatory grief related to potential future losses associated with the dementia diagnosis. People with dementia may also experience a bereavement, and dementia can be a complicating factor in dealing with the grief that comes with that. In this session we will present a brief overview of the research evidence relating to both anticipatory grief for people with dementia, and of grief in dementia relating to loss and bereavement. Using case studies drawn from Admiral Nurse practice, we will explore the evidence base for supporting anticipatory grief in people with dementia, including the use of Dignity Therapy, and consider how these therapeutic interventions can be adapted for use by any professional working with people with dementia. We will also offer ideas for how other evidence-based models of dementia care can be adapted for working with grief, loss and bereavement. Finally, we will make suggestions for further research in this area.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-02Residents in Dutch nursing homes: which subgroups are recognized?

Iris van der Weg[1], Anne Marieke Pranger[2], Alain Dekker[2], Irene Ijpma[2]
[1], [2]Department of Practice-Oriented Scientific Research (PWO), Alliade

In The Netherlands, approximately 121.000 elderly people live in nursing homes. Every resident has his or her own disabilities, diseases or syndromes. A resident on the waiting list is often offered a 'currently free place' in a nursing home. However, this may result in insufficient consideration about which residents could live together based on their support needs. The Dutch National Health Care Institute recently published the 'Appropriate Care Framework' (2022) which, among others, emphasizes the principle of 'appropriate care at the appropriate place'. It may be valuable to bring together residents (residents subgroups) with similar support needs that desire a similar approach as well as specific knowledge and skills of staff. For which subgroups could nursing homes create specific departments? The 28 Dutch nursing homes with the highest customer reviews were examined: which residents subgroups do they currently use? Moreover, literature was studied to identify potential, possibly still largely neglected, additional subgroups. This study showed that each of the 28 nursing homes used a rather classical division in departments for people with dementia and departments for people with physical syndromes or diseases. Diving deeper, few organisations also created departments for people with Korsakoff's syndrome, Parkinson's disease, gerontopsychiatric conditions and Huntington's disease. From literature, a number of additional residents groups were identified that the 28 organisations did not yet specifically address, among others dementia in people with intellectual disabilities, dementia in people with a migration background, dementia in people of the LGBTIQA+ community and elderly with morbid obesity. With regard to the future (increasing complexity and shortage of staff), the results from this study, discussed in more detail in the presentation, could help nursing homes to provide more appropriate care, for instance by working within a department with a subgroup-specific psychosocial support method.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-03Piloting a culturally adapted multicomponent START (STrAtegies for RelaTives) in N.Macedonia-results from feasibility and acceptability study

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Gill Livingston[3], Penny Rapaport[3]
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In this study we aimed to culturally adapt and test the feasibility of delivering START (STrAtegies for Relatives), a clinically and cost-effective multi-component intervention for family caregivers of people with dementia in N.Macedonia, a middle-income country with virtually no post-diagnostic support. First, we culturally adapted and translated the materials. Then, we conducted a qualitative study to collect feedback on the intervention from professionals working with people affected by dementia and family caregivers. We thematically analysed the results informed by the Framework for Cultural Adaptations of Scalable Psychological Interventions to further refine START to fit the Macedonian cultural and socio-political context. We are currently working on Phase 3 of the project-piloting the intervention to 10 caregivers in N.Macedonia and collecting data on its feasibility and acceptability delivered by trained and supervised facilitators. We will assess acceptability and feasibility quantitatively, and through interviews with participants and staff and examine whether immediate changes in caregivers' health outcomes were in line with previous studies. We will summarise findings from all phases. In phase 2, 14 caregivers (11 females, 3 males), two paid caregivers and three professionals working with people living with dementia participated in interviews (n=8) or focus groups (n=2). Caregivers perceived START as a potential tool to better cope in their caring roles. In the context of no other post-diagnostic support, stigma, and lack of information on dementia, START needs to be flexibly delivered alongside a culturally congruent explanation of dementia and caregiving. Data collection for the phase three will be completed in Summer 2024 and we will present these findings. START is the first non-pharmacological intervention for caregivers of people living with dementia to be translated and culturally adapted ready for implementation in North Macedonia. If feasible, we will provide the materials and a tool kit for implementation with recommendations for delivery.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-04Interventional study of psychosocial dietetic support for people living with dementia in the community identified as being at medium risk of malnutrition

Alexandra Rees
HYWEL DDA UNIVERISTY HEALTH BOARD

Background: Within Wales, people living with dementia within the community are accepted for dietetic support if they are screened as being at high risk of malnutrition. Evidence from the literature suggests that improving nutritional intake and preventing weight loss can reduce the risk of frailty and poor quality of life related to health. Aim: The aim of this study was to identify whether providing psycho-social dietetic support to people living with dementia screened as medium risk of malnutrition helped to prevent escalation of malnutrition risk and maintain wellbeing for longer. Methods: Referrals for people living with dementia within community settings across West Wales identified as being at medium risk of malnutrition were provided with psycho-social dietetic support. This included: Review of past and current physical health, Review of life story linked to dietary patterns, work and family relationships, food beliefs, Current dietary provision, intake, preferences and mealtime environment, A care plan was then formulated and implemented including ongoing regular reviews as clinically indicated. Baseline and post project data on weight and number of referrals to community dietetics was gathered. Results: 90% (n=19) of people who were suitable for intervention gained or maintained weight. 23% (n=5) initially lost weight but then stabilised their weight. Average weight gain was 2.4kgs - 5% (n=2) reduction in referrals to community dietetics for people living with dementia post study. Discussion: Earlier intervention prevented escalation of malnutrition risk and helped to maintain wellbeing. The study also highlighted that in many cases, a physical health cause rather than dementia related symptoms had affected nutritional intake. Correct identification of the root cause of a reduced intake was key to successful intervention. Conclusion: People living with dementia benefit from early and accurate identification of nutritional problems and appropriate interventions to help reduce their risk of malnutrition and maintain their wellbeing.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-05The MOMANT study, a caregiver support programme with activities at home for people with dementia: results of a randomised controlled trial

Sanne Balvert[1], Rose-Marie Dröes[2], Judith Bosmans[2], Martijn Heymans[2],

Erik Scherder[2], Maarten Milders[2]
[1]Vrije Universiteit, [2]

Aims: A growing number of people with dementia are cared for at home by informal caregivers, highlighting the need to support caregivers in this role. This study evaluated the effectiveness of an intervention combining two proven effective approaches: empowering caregivers and engaging the person with dementia in activities.
Methods: This randomised controlled trial compared outcomes in two groups: 76 dyads were included in the intervention condition, and 96 dyads in the control condition who continued with usual care. The intervention was a manual-based, caregiver support training consisting of 6 group sessions over two months, covering education about dementia, recommendations on how to deal with changes in behaviour and communication, how to cope with caregiving burden, and how to engage in stimulating activities. Training took place in small groups of caregivers led by healthcare professionals at dementia daycare centres. Randomisation occurred at level of the centre. Participants were assessed at baseline, and 3 and 6 months after on the following measures: quality of life; sense of competence; caregiving experiences; mood; pleasant activities; health care usage, activities of daily living; and global functioning.
Results: Preliminary results showed that immediately after intervention people with dementia engaged in more activities than those in the control group ($p<.05$). Caregivers in the intervention group were less positive about their caregiving experience than in the control group ($p<.05$). No differences on other outcome measures were found. Healthcare professionals and caregivers in the intervention condition were very positive about the intervention: the content was considered useful and caregivers indicated improved dyadic interactions.
Conclusion: This study underscores the demand among informal caregivers for information, emotional support, and services. While the intervention was effective in increasing the person with dementia's activity levels, further research is needed to explore its long-term effects and identify effective caregiver support components.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-06Young-onset dementia – how can admiral nurses meet the needs of families

Thea Sobers, Amy Pepper, Tia Cheung-Cook, Madeleine Walpert, Phil

Joddrell, Emma Wolverson, Karen Harrison Dening
Dementia UK

Background: Admiral Nurses are specialist dementia nurses who offer evidence-based advice and support to whole families affected by dementia. They are supported by the charity Dementia UK. Dementia UK has recently published its first research strategy, identifying young onset and rarer dementia as one of the three research priorities for the next three years. As part of this work, we have undertaken two concurrent systematic reviews looking at the needs of families affected by young-onset dementia and the ways in which Admiral Nurses may be able to meet these needs.
Methods: The review protocol was written with the support of an advisory group, made up of people with dementia, family carers, professionals and academics alongside the Dementia UK review team. Members of the advisory group have also taken an active role in the review itself, adding an important co-production element to the work.
The reviews will address the questions: 1. What are the psychosocial needs of children and young people (0–25 years) with a parent with young onset dementia across the illness trajectory (diagnosis to bereavement), 2. what are the psychosocial needs of people with dementia and their family carers, and 3. how might Admiral Nurses meet these identified needs?
A narrative review of the final included studies will be carried out and the identified needs will then be mapped against the domains of the Admiral Nurse Competency Framework to describe the ways in which Admiral Nurse can meet some of these.
Conclusion: We hope that findings of this review will help inform further development of the Admiral Nursing workforce. We also anticipate that the model of co-production used in carrying out these reviews will provide a useful blueprint for other researchers wishing to include people with dementia and their carers as partners in research.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-07Investigating strategies used by specialist nurses to incorporate multiple health conditions into care approaches for individuals living with dementia: a scoping review

Madeleine Walpert[1], Tia Cheung-Cook[1], Phil Joddrell[1], Thea Sobers[1],

Emma Wolverson[2], Karen Harrison Dening[1]
[1]Dementia UK, [2]

The prevalence of multimorbidity, defined as having two or more coexisting chronic health conditions, is twice as high among individuals living with dementia compared to those without dementia. The presence of multiple health conditions can result in complex cases and increased care needs. A dementia diagnosis can overshadow symptoms of other conditions, potentially leading to further health complications and exacerbated cognitive decline if additional conditions are not managed simultaneously. Despite extensive research on multimorbidity prevalence and patterns, how they are addressed in clinical practice is less clear.
We present the findings of a scoping review that investigated the role of condition-specialist nurses in providing holistic care for people living with multiple conditions. This review was developed in collaboration with an advisory group, made up of people living with dementia, family carers, professionals, and academics.
The results were analysed to explore the strategies supporting specialist case management of people living with multiple health conditions. The review focuses on the interventions that Admiral Nurses (dementia specialist nurses in the UK) use to incorporate physical and mental health conditions into their care provision. A range of interventions were identified including case-management, transitional care, support to self-manage, caregiver support and education and nurse-led interdisciplinary teams, and were spread across primary, secondary and community care services.
Findings highlight the vital role of Admiral Nurses in providing interventions and collaborative care coordination for individuals with multiple health conditions, supporting the need for their enhanced involvement in managing complex cases and holistic care.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-08Building a realist programme theory for olfactory stimulation interventions in dementia care: a mixed-methods approach

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University of Surrey, [3]Mental Health and Clinical Neurosciences, School of Medicine, University of Nottingham

Background: There is a growing interest in using olfactory (smell) stimulation in dementia care. This is due to the well-documented unique relationship between olfaction, memory, and emotional processes at the level of brain anatomy. Despite its increasing popularity in clinical practice, mixed effects have been reported on the benefits of olfactory stimulation interventions, and little is known about optimum delivery.
Aim: This study aims to develop an explanatory understanding of how, why and in what circumstances olfactory stimulation interventions can produce intended outcomes in people with dementia and care professionals in care home settings.
Methods: A realist review involving an iterative and multi-stakeholder phased approach to data collection and analysis is used. This includes the development of an initial programme theory by scoping the literature (Phase 1) and data gathered from a survey with academic experts and healthcare professionals (N=20) (Phase 2). Systematic searches of the evidence (Phase 3) and data from healthcare professionals, informal caregivers, and academic experts (Phase 4) are used to respectively refine and test the programme theory.
Findings: Outcomes, context factors, and potential mechanisms are identified from 62 included papers and 20 responses from the survey. Five potential causal explanations (Context-Mechanisms-Outcome configurations) are generated, describing how various positive outcomes may be achieved, both for residents and for care professionals. The emergent programme theory is confirmed or disconfirmed in relation to the literature through theoretical saturation and using additional follow-up data collection with stakeholders.
Conclusions: This study contributes to the development of theoretical understanding of the components and explanatory mechanisms through which olfactory stimulation interventions may generate changes in people with dementia and care professionals in care homes. This study offers an important contribution to the growing literature on methods to improve intervention design, and to practice by providing a framework for successful implementation.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-09Participatory development of a tailored video-feedback-intervention-programme for persons with dementia living at home and their carers

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Background: Person-centred care is the gold standard in dementia care, yet its implementation in everyday life is still a major challenge. Video-feedback is a promising dyadic intervention to improve person-centred communication. Video-Feedback consists of a joint reflection on video recordings of care situations in everyday life guided by a specialized nurse. Current evidence on video-feedback for persons with dementia and their carers is based on feasibility or pilot studies, while the target group itself is not actively involved in the development of the intervention. The aim of this study is the participatory development of a tailored video-feedback-intervention-programme for persons with dementia living at home and their carers. Method: A one-year participatory process with persons with dementia and their carers will result in a study protocol for an exploratory trial of a tailored intervention-programme using video-feedback at home. Persons with dementia and their carers will guide the study on three levels: a participant advisory board will supervise the process, four focus groups with participants will deal with key topics of the programme development and a joint group of participants and researchers will work on a study protocol. Key topics include collaboratively identifying barriers and facilitators to recruitment, everyday-life situations that can be improved by video feedback, meaningful outcomes of the intervention and developing a patient and public involvement plan for the subsequent study. Result/Discussion: Persons with dementia living at home and their carers will be actively involved in the development of a video-feedback-intervention for the first time. Together with the participants we will show how persons with dementia at home and their carers can be reached effectively, what situations they consider most appropriate for the intervention, what they see as meaningful outcomes of the programme and how they can be involved in the subsequent exploratory study meaningfully.

Innovation in care and research - Artificial intelligence

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-10How comprehensive “web search engine” and “AI bots” respond for queries related to dementia management?

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[1]Royal College of Surgeon Irelend, [2]Royal College of Surgeon Ireland

Artificial intelligence(AI) has been emerged as a promising technology in healthcare for answering questions and aiding in clinical decision-making processes. This research presents a comparative analysis of three technologies: Google(search engine), ThinkAny (AI search engine) and ChatGPT-3.5 (AI bot), used in the context of dementia management while focusing on the results generated by aforementioned and comparing with a standard clinical guidelines[1]. The approach relies on posing questions to these technologies and systematically analyse the generated responses. The methodology followed a series of statistical tests including the Friedman[2], Wilcoxon signed-rank[3] and Mann-Whitney U test(s)[4] to evaluate the responses generated by aforementioned and comparing against the standard clinical guidelines. Initial findings reveal significant variations in the responses generated by each technology in comparison with the standard clinical guidelines. Google exhibited the greatest deviation from the clinical guidelines across all questions indicating potential limitations in providing accurate information. ChatGPT-3.5 and ThinkAny demonstrated closer adherence towards clinical guideline for some questions but significant dispenses were also observed, indicating they lack the accuracy, credibility and depth provided by clinical guidelines. ChatGPT-3.5 and ThinkAny performed well in understanding the context when provided clear, direct and relevant information, but also compromises the accuracy. In contrast, Google's response lacks the depth and accuracy, that shows a gap in its ability to produce reliable response in comparison with the standard guideline. This research evaluates the performance of AI-tools while asking questions related to Dementia Management. It is evident that the full potential of using these tools have not been exploited in full essence but careful consideration(s) of their limitations and biases could ensure their meaningful use for researcher(s), medical professional(s) and caregiver(s). References: [1]Frederiksen-et-al-2020. European Academy of Neurology guideline on medical management issues in dementia. [2]Cleophas-et-al-2016. Clinical data analysis on pocket calculator.[3]Woolson-et-al-2007. Wilcoxon signed-rank test. [4]McKnight-et-al-2010. Mann-Whitney U-Test.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-11The challenges experienced by family members providing care and support for people living with dementia from a distance

Phil Joddrell, Karen Harrison-Dening, Thea Sobers, Madeleine Walpert, Emma Wolverson
Dementia UK

People living alone with dementia are a growing population who face unique challenges and significant inequity in accessing support. Whilst not everyone who lives alone will have a carer, many have families and friends providing support from a distance. Distance carers are a growing population who play a vital role in supporting people with dementia. Approximately 20% of all informal caregivers provide care from a geographic distance, many of whom are adult children of aging parents. Distance caring brings unique challenges, and whilst distance carers can experience personal growth and an enhanced relationship with the care recipient, they can also experience social isolation, distress and anxiety.

Research suggests that distance carers require support to enhance their effectiveness and to receive skills training for coping with feelings of guilt, burden, anxiety, and emotional distress. Specialist dementia nurses (known in the UK as Admiral Nurses) have expertise in supporting family systems, and are therefore well-placed to offer these resources provided that they have access to evidence-based interventions.

We present the findings of a systematic review that aims to synthesise the current evidence-base, addressing (1) the psychosocial needs of family members providing care to people living with dementia from a distance, (2) available solutions and tools to support distance caring, and (3) the potential role of specialist dementia nurses to meet these needs and facilitate solutions. The review is supported by an advisory group comprising people with dementia, family carers, specialist dementia nurses and academics. Group members have actively participated in the review process, contributing an essential co-production element to the work.

This review is being conducted alongside a review into the psychosocial needs of people with dementia living alone, to form a coherent approach to addressing an identified research priority of people with dementia living alone and families caring from a distance.

Patient pathways - Psychosocial interventions

QOP1. Quick oral presentations - Psychosocial interventions

QOP1-12Developing an information guide for people with dementia and their family carers on prescribing psychotropic medications for non-cognitive symptoms of dementia

Mairéad Bracken-Scally, Rachel Ward, Sheena Farrell, Paul Maloney, Seán O'Dowd
National Dementia Services, Health Service Executive

National Clinical Guideline No. 21 ("Appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia"), was published in 2019 to address a priority action of the National Dementia Strategy in Ireland; to develop guidance material on appropriate management of medication for people with dementia, in particular psychotropic medication, and to ensure resources are available in all relevant care settings. An implementation programme commenced in 2022 to implement the guideline on a phased basis across relevant care settings. A key output of the implementation programme has been an information guide for people with dementia and their family carers and supporters on prescribing psychotropic medication for non-cognitive symptoms for people with dementia. Both a Plain English and Easy Read version of this information guide have been developed. Both of these explain what psychotropic medications are and when they might be prescribed to a person with dementia. They also provide information on the possible side effects of using these medications why regular reviews of the medication are important, and where more information can be accessed. Three infographics have been developed to accompany the information guides, each of which illustrate a key message of the information guide and direct to the guide for further information. The development of these resources has been one of the primary communication and engagement activities of the Implementation Programme for National Clinical Guideline No. 21. Dissemination strategies for these resources are outlined, including inclusion of the information guide on the WHO Global Dementia Observatory. It is anticipated that these resources will contribute to improved quality of care and will improve health outcomes for people with dementia by, for example, increasing awareness of the risks of psychotropic medication and the alternative management strategies for non-cognitive symptoms in people with dementia.

Policy - Campaigning for change

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-01Navigating tomorrow: insights from Alzheimer Scotland's Commission on the future of long-term care

Vicki Cahill
Alzheimer Scotland

Alzheimer Scotland's Commission on the Future of Long-term Care conducted an extensive review of the current state of long-term care services and formulated recommendations to address existing challenges and shape the future of care provision in Scotland. Through a comprehensive assessment of policies, practice and stakeholder input, the Commission highlights fragility within the current system and identifies gaps in the provision of care and support. The Commission has considered new approaches to the delivery of long-term care, including looking to international examples of long-term care provision that better meets the needs of people with advancing dementia.
In response to growing demand for services and support and the desire for people with complex care needs to have increased choice, control and autonomy over their care arrangements, the Commission highlights the need for strategic planning, improved infrastructure, workforce development and an innovative approach to delivering person-centred care. It proposes a series of actions to promote quality, sustainability and equity in long-term care provision.
The Commission also explores the challenge of funding long-term care in the current landscape and has sought to establish a national conversation about the cost of care and how that financial burden is met. The Commission has developed a roadmap to transform the delivery and experience of long-term care and, through a concerted effort to implement its recommendations, Scotland can build a more resilient, inclusive approach to meeting the needs and preferences of people with complex care needs.

Policy - Campaigning for change

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-02A decade of advocacy: the Dementia Carers Campaign Network

Judy Williams[1], Helena Quaid[2]
[1]The Alzheimer Society of Ireland, [2]Chair of the Dementia Carers Campaign Network, The Alzheimer Society of Ireland

The Dementia Carers Campaign Network (DCCN), supported by The Alzheimer Society of Ireland, is an advocacy group of carers who support loved ones with dementia.
The DCCN was formed to facilitate the inclusion of the dementia carers' voice in policy affecting them and the people they care for. The group believes that their voice is important and must be included in public policy.
After a decade of advocacy, the DCCN has been involved in many policy consultations, has provided feedback on national dementia policy, has liaised with political representatives, and has taken part in many activities to raise awareness and increase visibility. The group has worked constantly to campaign for change for the better for carers, supporters and families of people living with dementia.
This presentation will show the history and highlights of a decide of advocacy, and the work behind the scenes to make this possible.

Policy - Dementia strategies

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-04Exploring dementia research knowledge translation strategies in Dutch academic health science centers: a multi-case study of Alzheimer Centers

Eden Zhu, Martina Buljac, Kees Ahaus, Robbert Huijsman
Erasmus University Rotterdam

Background: Research products generated in traditional university settings, such as social and behavioral interventions, often remain siloed within their research disciplines. Implementation science can be leveraged to navigate complexities in research innovation systems to enhance research outcomes. The Netherlands established five specialized academic health science centers, referred to as Alzheimer Centers, to structurally facilitate the creation, adaptation, dissemination and implementation processes for Dutch dementia research.
Objectives: This study uses an implementation science-guided approach to explore strategies employed by each Alzheimer Center, across stages of the 'knowledge-to-action' (KTA) framework, which includes creating knowledge, assessing barriers to implementation, and monitoring and evaluating implementation.
Methods: Individual semi-structured qualitative interviews were conducted with respondents from each Alzheimer Centers, and respondents were selected through purposive (snowball) sampling. Interviews were conducted in-person and virtually through Microsoft Teams, and

all were audio-recorded, transcribed verbatim, and the analysis was guided by the dimensions of the KTA framework.
Result: Knowledge creation, and the translation of research findings into research knowledge products, was facilitated through strategies, such as establishing relationships between researchers and patient groups, facilitated in ‘memory clinics’ and ‘client panels’ at the Alzheimer Center, which provided researchers the opportunity to involve end-users in research product development. Implementation and dissemination of research knowledge products was often facilitated through establishing early formal partnerships and engaging well-networked external intermediary organizations and university-based technology transfer offices to facilitate implementation.
Conclusion: The varied strategies identified across each Alzheimer Center suggests a connection between the teams’ capacity to utilize research and the societal impact of research. Results also suggest to systematically examine the allocation of resources in the research ecosystem to inform future research implementation efforts and enhance research utilization outcomes. Future studies may structurally explore the role of other stakeholders in the research ecosystem and their impact of implementation and research impact.

Policy - Dementia work force

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-05Intellectual disability and dementia: co-development of a social enterprise to train the health and social care workforce

Karen Watchman, Karen Watchman
University of Stirling

SquarePeg Training has been developed as a not-for-profit social enterprise by Professor Karen Watchman as a spinout company at the University of Stirling, Scotland. She is working alongside Training Associates with intellectual disability who co-develop dementia resources and some of whom will co-deliver dementia training. A social enterprise in the UK is a not-for-profit business trading for a social purpose. The aim is to enable change in organisational practice within the health, social care and NGO workforce and create a cultural shift that avoids organisations 'reinventing the wheel' with each new diagnosis of dementia in people with intellectual disability.

SquarePeg Training provides a one-day course on intellectual disability and dementia in both online and face-to-face formats. Ongoing access to a virtual toolkit provides course attendees with regularly updated information after the training. As a not-for-profit social enterprise, income from course fees are fed directly back into the business to ensure appropriate inclusion and involvement of Training Associates with intellectual disability.

SquarePeg Training addresses the specific needs of people ageing with intellectual disability and dementia. It enables health and social care organisations to actively demonstrate how they are meeting indicators and targets of national dementia plans and regulatory requirements in relation to diversity, equality and equity. Pre and post evaluation of 102 intellectual disability social care staff between Jan-Mar 2024 showed an increase from 51% to 92% in perception of ways in which support may be provided and individualised. Ongoing contact is maintained with course attendees to monitor longer-term impact in practice.

SquarePeg Training will be launched to a European audience at Alzheimer Europe. Examples will be shared of dementia training materials co-designed by people with intellectual disability whose contribution has led to greater understanding of lived experience of intellectual disability and dementia and improved workforce development outcomes.

Policy - Dementia work force

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-06The role of clinical pharmacists in primary care in supporting older people and people with dementia

Alice Burnand[1], Abigail Woodward[2], Jill Manthorpe[2], Yogini Jani[2], Mine Orlu[2], Kritika Samsi[2], Victoria Vickerstaff[2], Greta Rait[2], Kumud Kantilal[2], Jane Wilcock[2], Nathan Davies[2], N/a N/a[2], N/a N/a[2], N/a N/a[2], N/a N/a[2], N/a N/a[2]
[1]University College London, [2]

Background. In most countries primary care staff are often the first point of contact for people with dementia, many of whom often have multiple long-term conditions, and on

several medications. In the UK clinical pharmacists based in GP practices is relatively new and they may become integral to the primary care team. These pharmacists have the potential to support people with dementia with their medication and disease modifying treatment. There is limited knowledge about clinical pharmacists' experiences in supporting people with dementia and how they may become integrated within work with primary care teams.

Objective. Building on a literature review and survey, we explored the perceptions and experiences of clinical pharmacists working in UK general practice about their support for people affected by dementia.

Method. Thirteen semi-structured interviews were conducted with clinical pharmacists (December 2022-January 2024) across England. Data were analysed using reflexive thematic analysis.

Findings. Four main themes were generated: 1) moving beyond medication use and prescribing; 2) preparation for the role and learning on the job; 3) supporting diverse needs in diverse populations; 4) the potential for a clinical pharmacist to be a key component of primary care systems. Pharmacists reported providing holistic and proactive care, although they predominantly focused on medication reviews. They discussed how their role also supported aspects of social care. Challenges with service delivery included difficulties establishing themselves within the team, compounded by poor understanding of their role by patients. Interviews highlighted a lack of training around dementia for clinical pharmacists.

Conclusions and implications. A greater focus on the potential role of clinical pharmacists in dementia care systems is needed. Pharmacists' unique skills can support people with dementia beyond simply medications, but work is needed to consider how to best utilise and integrate clinical pharmacists in dementia care pathways and enhance dementia training.

Policy - Dementia work force

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-08Leading change in residential care: A qualitative study to develop Dementia Care Mapping for future implementation.

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Keywords: Residential care, Dementia Care Mapping, Person-Centred Care, Practice Development, Workforce Development, Long-term care
Background: Dementia Care Mapping (DCM) is an observational tool used to deliver person-centred care (PCC) for people living with dementia. While research has demonstrated the positive impact of DCM in residential care, more needs to be understood about staff's application of PCC in practice, and implementation of DCM.
Aims and methods: A constructivist grounded theory study to understand the perspectives, experiences and understanding of residential care staff, and DCM mappers, in implementing PCC. It aimed to explore ways to improve the implementation of PCC using DCM. Data was collected using online and telephone interviews with 15 health and social care staff.
Findings: This study offers a nuanced understanding of PCC within residential settings, focusing on the formulation of care plans and its implications for the practical implementation of PCC principles. The study reveals a complex interplay between managerial perspectives, staff practices, and organizational dynamics. While care plans are deemed essential documentation for individualized care, their creation often imposes administrative burdens, detracting from meaningful interactions with residents. DCM participants highlighted the challenges faced by care staff in residential care, including understaffing , and a constant cycle of addressing urgent needs within the constraints of time and resources. This negated full engagement in the comprehensive person-centred approach of DCM.
Conclusion and implications: The study highlights the importance of reconceptualising PCC beyond mere documentation, emphasising the significance of everyday actions and interactions that prioritise residents' individuality and well-being. Participants' perspectives shed light on the inherent conflict between the concept of PCC and its practical application, especially in the context of formulating care plans. Despite efforts to tailor care plans to residents' needs, the emphasis on paperwork may hinder the value of spontaneous, person-centred interactions carried out by care staff.

Policy - Dementia work force

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-09What health and social care professionals can learn from people with dementia and their family caregivers: a qualitative exploration.

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[1]Windesheim University of Applied Sciences, [2]Windesheim university of Applied Sciences, [3]Utrecht University

Dementia care is transitioning from medical-somatic to more psychosocial care approaches. This transition requires new ways of working, and consequently different competences of health and social care professionals who play an important role in enabling to live well with dementia. However, training and development programs for these professionals often lack focus regarding what is important to live well with dementia for those with lived experiences. The Enable-dem project was initiated to foster lifelong learning and professional development of health and social care professionals, in such a way, that living well with dementia is fostered. As part of this project, we conducted a qualitative study in which we collected the perspectives of people with dementia (n=12) and their family caregivers (n=7) on how to equip these professionals more effectively to support living well with dementia. Data were collected from August 2023 until May 2024, using several qualitative methods based on participants' preferences: narrative (walking) interview, photo-elicitation, group interview, home tour and observation. We discussed several topics, such as 'what professionals should know about living with dementia', 'what professionals should particularly avoid doing', and 'what professionals can learn from their perspectives'. The preliminary results show that people with dementia find it important that professionals stimulate them to try out new things (e.g. build a birdhouse or start painting) and to focus on their remaining capacities : ''We already feel the pain of losing ourselves, so do not focus on what is lost''. Besides, caregivers gave an example that (future) professionals would benefit from listening to first-hand experiences to understand how it feels to live with dementia, as opposed to relying solely on second-hand, factual descriptions in textbooks. These results will be used to develop content and strategies to innovate lifelong learning and development of (future) professionals in dementia care and support services.

Policy - Dementia work force

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-10Mapping multiple health conditions and deprivation to the provision of specialist dementia nurse services in the UK.

Madeleine Walpert, Tia Cheung-Cook, Phil Joddrell, Emma Wolverson,

Karen Harrison Dening
Dementia UK

Research has identified an association between deprivation and multiple health conditions. There is a high prevalence of comorbid health conditions among people living with dementia (PLWD). Comorbidity is a risk factor for reduced quality of life and poses significant care challenges; such as accelerating the progression of dementia or masking other health conditions. It is critical that healthcare services prioritise the ongoing assessment and management of additional health conditions among PLWD, highlighting the need for specialist nurse services and targeted case management.
Dementia specialist nurses (known as Admiral nurses in the UK), play a vital role in providing holistic support to PLWD. This study aimed to evaluate the geographical demand for specialist dementia services in relation to the prevalence of additional health conditions and case complexity. It also seeks to analyse the distribution of Admiral Nurse services across areas with varying levels of deprivation and health comorbidities.
Data were collected on the location of Admiral Nurse services, levels of deprivation and co-morbidities across the UK. In addition, services provided information on their management and support to PLWD and comorbid health conditions. The services were purposively sampled to represent a range of geographical locations and areas of healthcare supported by Admiral Nurses.
Results demonstrate the levels of complexity across the variety of settings that Admiral Nurses work in, across the trajectory of dementia. Another finding was the inconsistent recording of additional health conditions among individuals with dementia and gaps in the distribution of Admiral Nurse services, in areas of higher deprivation access to services was found to be more limited.
Recommendations are proposed relating to the recording of data on health comorbidities as well as the distribution of Admiral Nurse services to ensure equitable access in line with the level of needs.

Policy - Dementia work force

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-11Caring for people living with dementia in their own homes: A qualitative study exploring the experiences of registered nurses within a district nursing service in the UK

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[1]University of West London, [2]Central and North West London NHS Foundation Trust, Gospel Oak Health Centre, [3]City, University of London

National UK policy advocates timely dementia diagnosis, access to high-quality health and social care post diagnosis, enabling people to live in their homes for longer, and supporting people to die with dignity in a place of their choosing. Integration of dementia treatment and care into primary care is recommended to meet the long-term needs of people with dementia. District nursing services (DNS) provide care for people with long-term conditions at home and the number of people with dementia on their caseloads is increasing.

A pragmatic qualitative study using an interpretivist approach was undertaken to gain insight into the role and experiences of nurses caring for people living with dementia at home. We conducted semi-structured interviews with ten nurses working within the DNS. Data were analysed using a thematic approach. Participants described having considerable contact with people with dementia and managing increasingly complex situations despite little training in this field. Five main themes were identified: *Care takes place within the home; Taking it in their stride; Coping with challenges; Support networks*; and *What would help*. The ability of participants to meet a diverse range of care needs was evident. The study enables a better understanding and appreciation of the role of DNS in supporting people with dementia to live at home. Care was provided across the illness trajectory from detection and diagnosis of dementia through to end-of-life and the involvement of DNS was instrumental across all stages. Understanding the contribution of DNS is important for defining how dementia care can become effectively integrated into primary care. Our findings suggest new models of working are needed, that can factor in additional time and staffing such as specialist nurses in dementia and palliative care, to ensure DNS have the necessary resources to effectively meet the needs of people with dementia on their caseload.

Policy - Dementia work force

QOP2. Quick oral presentations - Dementia strategies and policies

QOP2-12Education and training in dementia for health and social care professionals-from national to European strategic principles.

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The health and social care dementia workforce are subject to an ever-changing landscape of essential and desirable training. Education and competence-based standards vary across countries and depend on job roles. Some European countries already have dementia education and training standards and frameworks. In the UK, educators across 70 Higher Education Institutes formed the Higher Education Dementia Network (HEDN) to develop a collective and unified higher educational response to supporting dementia education. HEDN provides opportunities to address challenges in the field, contribute to the evidence base, and provide peer support. Its flagship '*Curriculum for Dementia Education*' (2013) project provided suggested curriculum content and learning objectives for UK dementia education. The Network's new 5 Year Strategy (2022-2027) has 8 objectives, including collaborating with those affected by dementia and global educators to support the evolution of Knowledge and Skills Frameworks and the development of a global dementia educator network. In response, the HEDN Team reached out to the INTERDEM community to collaboratively develop a new taskforce focusing on Dementia education and training. Developing the Taskforce will be presented.

The European dementia education landscape suggests the existence of Dementia Knowledge and Skills Frameworks varies across countries. Limited research evaluates the widespread application or impact of these frameworks in improving the knowledge and skills of health and social care professionals supporting people with dementia and family caregivers. This suggests a need for a new INTERDEM Taskforce to review current European educational provision. The aim of the group (including people with dementia and caregivers) is to scope existing educational provision and frameworks; identify the key components of programs i.e. content, effective delivery approaches; and assessment principles; and collaborate on new educational opportunities. Ultimately, the aim is to develop guiding educational principles and strategies, which could underpin a European Knowledge and Skills Framework and Standards.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-01The innovative AI-Mind data collecting framework - a user-centric way of diagnosing mild cognitive impairment

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AI-Mind stands at the forefront of neuroscience innovation in Europe, offering a pioneering completely automated platform designed to detect early signs of mild cognitive impairment (MCI) and predicting dementia risk. With an unwavering commitment to data security and compliance, AI-Mind adheres to the strict guidelines of the Data Protection Act and regulatory standards, ensuring the utmost protection of sensitive information. The core platform contains data of over 1000 European citizen that are prospectively monitored by diverse biological measures (EEG, blood, digitalized cognitive assessment, CSF/PET, MRI, metadata) for algorithm development. Our data governance and management processes guarantee FDA and EMA compliance, maintaining excellent data integrity and consistency and should inspire others to follow. AI-Mind rises to the challenge of predictive modeling by focusing on controlling confounding factors, employing cutting-edge techniques to enhance predictive accuracy and clinical validity. We recognize the critical challenge and importance of how to collect data, integrating confounds and uncertainty in predictive AI modeling for medical use, ensuring that our new biomarkers derived from brain data are reliable and clinically relevant. Therefore, as a prerequisite, our platform provides comprehensive guidance for clinicians and researchers, from standardization and automation to methodological and statistical insights, ensuring the reliability and validity of new biomarkers derived from brain data. We are pleased to introduce and inspire the AE conference audience with fully automated, standardized international diagnostic data collection procedures. These are designed to replace traditional, human-centric, phenomenological descriptions of behavioural changes in mild cognitive impairment with a standardised, automated diagnostic procedure based on a biological defined AI tool development.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-02Personalized dementia education using AI: interprofessional needs analysis & user-centred prototype evaluation for developing digital learning content

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People with dementia (PwD) require professional care that demands well-trained healthcare professions. Continuously updating dementia-related knowledge on a trans-disciplinary level is important. Digital media are increasingly being adopted in the healthcare education allowing adaptation to individual needs and learning preferences. The use of Artificial Intelligence (AI) can provide support, but concrete solutions are currently lacking. The aim of MINDED.RUHR project is to develop automatized personalized learning content using AI. The sub-project focuses on the participatory development of needs-based content as well as its preparation and initial evaluation by future users. The research design combines various methods of participation. Focus group interviews with professions in dementia care focus on dementia-specific training needs and individual learning requirements. On this foundation, a learning preference matrix and learning materials were developed and used to create prototype learning nuggets. In co-design workshops, the prototypes are evaluated for usability, design and content suitability. Finally, expert interviews are conducted for quality approval of the learning nuggets. Focus group interviews (n=8) result in a list of content-related learning needs around three topics: forms and stages of dementia, communication techniques and changes in behavior. The professionals prefer strategy of peer learning In co-design workshops (n=39) the proximity and identification of the examples from practice and comprehensibility and need of the content were positive highlighted. The experts (n=5) pointed the avatars as digital colleagues out and critically suggested improvements in practical tasks. This sub-project provides insights into learning needs and preferences of professionals in dementia care. Behavioral changes are a challenge for every profession. So it is important to impart knowledge about communication techniques and clinical pictures. The importance of adaptive learning paths tailored to healthcare professionals is highlighted. Future education could take advantage of informal learning strategies and practice-based content for effective knowledge transfer.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology



QOP3-03A conceptual health-economic model to assess the impact of artificial intelligence-based care technology in dementia

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Artificial intelligence (AI) innovations, such as social interactive agents and assistive devices, hold promise for improving the daily coping ability of Persons with Dementia and caregivers. However, questions arise regarding their cost-effectiveness. Early Cost-Effectiveness Analysis allows to explore their potential impact and guide further research. We aim to conceptualize and develop a health-economic model for assessing AI-based care technology developed in QoLEAD project in dementia. We reviewed current model-based health-economic evaluations of dementia interventions and their recommendations on model structure. We conducted ten unstructured focus group interviews with experts in AI, industrial design, cognitive neuropsychology, dementia care and health economics in the Netherlands. In an iterative approach, we integrated this knowledge to determine the model design, structure for simulating disease progression and care, and approaches for quantifying intervention effects and extrapolating intervention effects beyond available short-term evidence. Most existing models focused on pharmacological interventions, which were considered inadequate for capturing the intended outcomes of AI-based interventions. We conceptualized a cohort state transition Markov-type model design, with disease progression through transitions between mild, moderate, and severe dementia states, and the risk of death in each state, with care setting transitions across informal care, home care, and nursing home placement. The approach for quantifying the effectiveness of AI interventions was conceptualized by intermediate outcomes including care-giving hours, activities of daily living, caregiver burden and coping ability, neuropsychiatric symptoms. These outcomes predicted transitions in formal care settings. The model simulates changes in care setting duration compared to usual care pattern, which will be translated into incremental cost per quality-adjusted life-year (QALY). Our model conceptualization focused on estimating the key transitions along the care pathway instead of predicting disease progression. This approach may provide a generalizeble framework to conduct cost-effectiveness analysis for non-pharmacological interventions in dementia.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-04How does generative AI imagine people with dementia?

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There has been a rapid expansion in use of generative artificial intelligence (AI), including AI image generators. Stereotypical portrayals of people with dementia exist in media and can reinforce stigma. Image generators are trained on existing media, potentially building stigmatizing bias into new AI tools. This study investigated whether AI image generators exhibit potentially stigmatizing biases regarding people with dementia. Two popular AI image generators were investigated, Dall-E 3 and Midjourney V6. Three control prompts ("Photo-realistic portrait of a person/man/woman") were adapted by incorporating preferred terminology for two further conditions (older adult, person with dementia). 468 images were generated. Content analysis of images was performed, where data on affect, posture, setting (indoors vs outdoors), and presence of assistive technologies (e.g. walking stick or frame etc.) were extracted. Results for older adults, people with dementia and control prompts were compared for each AI model with Chi-2 tests. Text descriptions of each image were generated using Midjourney's "describe" function and were analyzed by inductive thematic analysis. Results are expected by September 2024. Primary quantitative analyses will reveal whether AI image generators more frequently portray people with dementia exhibiting negative affect, passive posture, indoors, or with assistive technologies. Secondary quantitative analyses will identify whether specific acceptable terminology exacerbates or minimizes stigmatizing biases. Thematic analysis of image text descriptions will provide insight into identified stigmatizing biases. AI image generators may be useful tools for easily generating media content. If used appropriately, this could support advocacy and science communication around dementia. However, if AI tools exhibit stigmatizing biases, then indiscriminate use may be harmful, and policies for using generative AI would be needed. If biases are found, this study will inform policies and decision-making, including choices of tool and prompt terminology to minimize stigmatizing bias.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-05Prediction of Alzheimer's disease using an AI driven screening platform: PREDICTOM study design

Anna-Katharine Brem[1], Zunera Khan[2], Mark Ashworth[2], Nicholas Ashton[2], Sigurd Brandt[2], Anne Corbett[2], Ana Diaz[2], Holger Fröhlich[2], Martha Therese Gjestsen[2], Dianne Gove[2], Sandeep Kaushik[2], Gaby Marquardt[2], Matthias Müllenborn[2], Spiros Nikolopoulos[2], Lucas Paletta[2], Dag Aarsland[2]
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Early prediction of Alzheimer's disease (AD) is an urgent health challenge. Technological developments in (neuro-)physiological and digital biomarkers suggest that the early diagnostic process can take place in the home-setting. The PREDICTOM study aims to evaluate promising biomarkers in the home-setting via an artificial intelligence (AI) driven platform. The PREDICTOM (Prediction of AD using an AI-driven Screening Platform) study includes the development and evaluation of a cloud-based platform, which is used to digitally collect, store and analyse data using AI algorithms to provide an individual risk assessment for the development of AD. It includes participants from 7 European sites (Norway, UK, Belgium, France, Switzerland, Germany, Spain). In the first cohort phase (Level 1), participants (N=4000, >50y) with an increased risk of developing AD will undergo home-based screening including digital (cognition, hearing, eye-tracking, questionnaires) and physiological (finger-prick blood, saliva, stool) biomarkers. In the second phase, participants whose risk was identified as being high (N=415) versus low (N=200) will undergo a simple in-clinic assessment, which can be implemented in a GP setting, including EEG, MRI, blood, cognition, hearing, and eye-tracking (Level 2). A diagnostic evaluation including cerebrospinal fluid, plasma, or amyloid PET measures (Level 3) to confirm or rule out AD pathology will be completed. A subset of participants will complete a follow-up visit after 12 months. The study protocol received feedback from lay people involved in the project's Advisory Board and we aim to implement a feedback system for participants and care providers. First results are expected to be disseminated in 2025. PREDICTOM will develop and evaluate AI-driven algorithms for the early detection of AD using existing and novel home-based biomarkers with the aim of incorporating its use into the clinical pathway for the early screening and stratification of individuals at risk of AD.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-06Results of an individualized computer-based cognitive training for community-dwelling people with mild cognitive impairment:the benefits of a computerized learning system

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Computer-based cognitive training (CCT) has shown to enhance functions in individuals with mild cognitive impairment (MCI), particularly when incorparting a learning system that utilizes machine learning to tailer exercises to indiviual's optimal performance level, facilitating personalized training. In our study we created two cognitive training programs: individualized CCT (iCCT) utilizing machine learning for the intervention group, and basic CCT (bCCT) for an active control group. The objective was to ascertain whether iCCT led to significantly greater improvements in overall cognitive function among individuals with MCI compared to bCCT over a six-month period. This study, a double-blind randomized controlled trial, was conducted entirely online. The cohort comprised 89 community-dwelling individuals in Germany diagnosed with MCI through psychometric assessment. iCCT targeted various cognitive domains, particularly working memory, visuoconstructional reasoning, and decision-making, while bCCT comprised simpler tasks. Both programs were designed for home use. Cognitive function was evaluated using the Montreal Cognitive Assessment (MoCA) at baseline and after six months. During the presentation, the training programs will be shown and the promising results discussed.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-07AI-driven linguistic profiles for improved dementia care

Stylianos Kokkas[1], Sofia Segkouli[2], Konstantinos Votis[2], Nikolaos Laloumis[2], Ioanna Drympeta[2]

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Cognitive and linguistic deficits serve as initial indicators of dementia [1]. This research leverages advanced Artificial Intelligence (AI) technologies for dementia onset prediction through language performance analysis. Linguistic markers and overall language competence are sensitive indicators of mental dysfunction and early dementia stages. The study aims to identify specific linguistic patterns that indicate early cognitive decline [2]. The methodology emphasizes deep learning models to process and analyze large datasets of linguistic responses in user-friendly linguistic games [3]. The AI system employs Convolutional Neural Networks (CNNs) and Recurrent Neural Networks (RNNs), particularly Long Short-Term Memory (LSTM) networks, to analyze spoken and written discourses, capturing nuances that traditional assessments might overlook. Feature extraction techniques quantify various aspects of language use, such as lexical richness, syntactic complexity, and semantic coherence. These features are inputs to the AI models, trained to classify cognitively healthy adults, adults with subjective memory complaints, and stages such as mild cognitive impairment (MCI) and dementia.
Preliminary results indicate that AI-driven analysis of linguistic game performance can accurately differentiate between healthy individuals and those with early signs of cognitive decline. The added value of this research is that specific linguistic markers can complement clinical variables to provide accurate prognosis and effective interventions tailored to individuals' cognitive and language profiles [4]. Furthermore, this AI approach entails scalability and adaptability for widespread screening in diverse populations. This study highlights the significance of advanced AI in future dementia research and care strategies for early prediction and prevention.
This paper is part of the COMFORTAGE project "Prediction, Monitoring and Personalized Recommendations for Prevention and Relief of Dementia and Frailty" that has received funding from the European Union's Horizon 2020 research and innovation program under grant agreement No. 101137301.

Innovation in care and research - Artificial intelligence

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-08Amplifying inclusive voices in AI4HOPE value-sensitive co-design journey for digital (AI-based) dementia palliative care



Rosa Almeida[1], Raquel Losada[2], Diana Marques[2], Dianne Gove[3], Daphné Lamirel[3], Lukas Duffner[3], Cathy Payne[4], Izidor Mlakar[5], Lukas Radbruch[6], Suzanne Timmons[7], Aljaž Hölbl[8], Maria Luísa Castro Guedes[9], Matthew Allsop[10], Marteyn van Gasteren[11], Riku Klén[12], María Soledad Rojas Diaz[2]
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Background: Artificial Intelligence Based Health, Optimism, Purpose, and Endurance in Palliative Care for Dementia (AI4HOPE; Grant Agreement No: 101136769, 2024-2027), a Horizon Europe-funded initiative, aims to innovate palliative care for dementia through participatory design of digital tools, ensuring the creation of solutions that are deeply rooted in the values and needs of its users. Its proposed Participatory frame emphasizes a value-sensitive co-design approach, focusing on the integration of Public Involvement activities and the establishment of local action groups to enhance the development process. Participatory approach: Various participatory activities will be planned and implemented to engage diverse stakeholders - including people with dementia, caregivers, healthcare professionals, advocacy groups and policymakers across multiple European sites. Through extensive consultation and co-design, the project seeks to identify and address priority care-support needs within the cultural, familial and social contexts of individuals living with dementia. Adopting a Value-Sensitive Co-Design Framework, AI4HOPE is committed to a design process that respects the dignity and needs of people with dementia. This approach ensures the development of ethically sound and practical digital tools from a user-centred perspective. It also facilitates iterative co-creation and real-time feedback integration. AI4HOPE participatory design process is structured to foster empowerment and active involvement, allowing stakeholders to influence the project outcomes significantly, aiming to ensure solutions developed are grounded in real-world needs but also aligned with ethical communication standards advocated by Alzheimer Europe, particularly emphasizing respect and dignity for people living with dementia. Conclusion: AI4HOPE will pilot a participatory design process implemented in healthcare technology development, particularly in sensitive areas such as palliative care for dementia. By adhering to a value-sensitive design approach, the project anticipates developing ethically sound and culturally competent digital tools for dementia palliative care, ultimately aiming to enhance the quality of care and life for people with dementia.

Innovation in care and research - Assistive technologies

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-10Eye-tracking and visual processing tests for assessing driving ability in dementia and mild cognitive impairment background: driving cessation can

Agmet Begde, Eef Hogervorst, Thom Wilcockson, Andrew Morris, Diane Gyi
Loughborough University

Background: Driving cessation can significantly impact independence and quality of life for people with dementia (PwD). Assessments to determine driving fitness are critical for balancing safety and autonomy. This study investigated the sensitivity and specificity of eye-tracking and visual processing tests in evaluating driving abilities among cognitively intact and impaired older adults. Methods: 24 participants (11 with cognitive impairment, 13 healthy controls) completed cognitive assessments (MMSE, HVLT, VST, CBT), eye-tracking tasks (antisaccade, prospective eye movements), and a computerised hazard perception test (HPT). Correlation analyses and ROC curves explored relationships between measures and driving performance. Results: The cognitively impaired group performed significantly worse on HPT ($p<0.01$). VST and HVLT showed strong correlations with HPT ($r=-0.83$, $r=0.837$) and high discrimination in predicting HPT pass/fail (AUC=0.93, 0.94). Optimal cut-offs were VST>1935ms (sensitivity 100%, specificity 86%) and HVLT<23.5 (sensitivity 87%, specificity 100%). MMSE and CBT also demonstrated good discriminatory power (AUC=0.84, 0.83). Conclusions: Visual processing speed and verbal memory tests demonstrate high sensitivity/specificity for screening driving fitness among PwD. Combining assessments with qualitative perspectives could facilitate individualised interventions to promote independence while prioritising safety.

Innovation in care and research - Assistive technologies

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-11How people living with dementia support their well-being with everyday technology

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There are few bespoke technologies for people living with dementia. However, consumer technologies such as tablets and voice assistants contain multiple functions that can benefit people with and without cognitive impairment. This study set out to explore what technologies people living with dementia use and what they use them for. Nine individuals (4F/5M) living with dementia aged between 71-84 years, agreed to participate in Technology Tours of their home, followed by an interview. The participants guided researchers around their homes identifying technologies they use in their everyday lives. Participants also completed a cognitive assessment and a wellbeing measure, which revealed levels of well-being above the national average. The findings revealed an average of 12 technologies used around the house that fulfilled various functions for the individuals. Thematic analysis revealed usability, maintaining enjoyable activities, connectedness, safety and independence as motivators of technology use and contributors to maintenance of well-being. The findings highlight the motivation of people living with dementia to adopt technologies in their everyday lives and the benefits they experience. This should inspire both awareness raising of existing devices and functionality and increased development of bespoke technologies to meet the specific needs, desires and priorities of people living with dementia.

Innovation in care and research - Assistive technologies

QOP3. Quick oral presentations - Artificial intelligence and technology

QOP3-12Mindful waters: digital aquariums as social catalysts in dementia care

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Background: Some forms of dementia are associated with social withdrawal, mood changes, and decreased interaction. Existing interventions, such as animal-assisted therapies and robotic companions, have shown potential in enhancing well-being but come with limitations like maintenance costs and complexity. Mindful Waters, an interactive digital aquarium, was developed to promote social interaction and engagement among people with dementia (PwD) through digital fish interactions. Methods: Mindful Waters combines features of aquariums and public interactive displays, allowing PwD to interact with digital fish using hand gestures and a fish-feeding device. The system aims to trigger conversations, encourage social interactions, and enhance participants' mood and self-image. The pilot study involved two interactive sessions at a community center and an independent living care facility, with situated observations and interviews conducted to assess user engagement, motivation, and experience. Participants' interactions were recorded, and participation patterns were modelled using the Participant Journey Map (PMJ). Results & Discussion: The study revealed that Mindful Waters effectively engaged PwD, promoting social interactions and conversation topics related to aquariums and fishing. Participants showed initial hesitation but became more willing to interact after observing others. The system facilitated social interactions, with some participants encouraging others to join. The PMJ was useful in tracking user engagement phases, although adaptations were needed for the care facility setting. User experience feedback was generally positive, with participants appreciating the visual appeal and simplicity of the interactions. However, some participants, especially those with advanced dementia, found it challenging to interact due to mobility and cognitive issues. Overall, Mindful Waters demonstrated potential as an engaging tool to enhance social connectedness and well-being in PwD. While our early results suggest that Mindful Waters can be a beneficial tool for dementia care, further research with longer-term deployments and more diverse participant groups is needed to optimize its design and functionality.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-01Empowerment groups for people living with dementia from indigenous and ethno-cultural communities

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Aims: This paper will report on the first year of a two-year study aiming to support and build capacity of partner organizations, empowerment facilitators/staff and members of engagement and empowerment groups in South-Western Ontario, Canada. The focus of this paper will be the experiences of developing empowerment groups from First Nations communities and diverse ethnocultural groups of people living with dementia from these communities. The project is the first of its kind to engage with indigenous peoples to create an empowerment group model based on the communities lived experiences and world views of dementia.
Methods: A mixed method approach with 4 primary data collection methods: 1. periodic co-design workshops with all partners, 2. empowerment group facilitators reflective journaling about the process of activities as they are planned and executed, 3. data collected using questionnaires and surveys from participants of all community-based events, and 4. interviews with the empowerment facilitators.
Findings: The paper will share examples of community-based activities generated by the empowerment facilitators as they work towards establishing empowerment groups embedded within a First Nations community and a region with highly diverse ethnocultural communities. The challenges of both creating and evaluating empowerment groups as they evolve will be considered as well as sharing the lessons learnt and opportunities for further development.
Conclusions: The process of establishing empowerment groups with diverse communities is challenging but also rewarding. Adapting existing approaches and models of empowerment provides a basis to create community driven groups that respond to the needs and aspirations of communities.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-02Exploring the role of community pharmacists in improving help seeking for dementia among Black African and Caribbean people in the UK

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Background: Black, Asian and Minority Ethnic (BAME) people continue to present later to healthcare services for help-seeking related to potential dementia symptoms and associated diagnosis. This impacts timely diagnosis and subsequent access to post-diagnostic interventions and support. While interventions to support help seeking have been developed for other BAME communities, there is a paucity of research involving the Black African and Caribbean (BAC) community. Furthermore, no previous research has considered the potential role of the community pharmacist. This research explored the potential for community pharmacists to support improved help-seeking for dementia among the BAC population.
Methods: A multi-methods project involving two surveys (with 113 community pharmacists and 141 BAC participants) and interviews with 36 participants (10 community pharmacists, 6 BACs living with dementia, 10 family carers of BACs living with dementia and 10 non-carers).
Results: There is a complex relationship between BAC people, dementia help-seeking and community pharmacists. Stigma, religious/cultural beliefs and poor dementia knowledge were barriers to help-seeking in the BAC community. Community pharmacists believe they were accessible and visible and therefore well suited to supporting timely help seeking for dementia among BAC people. BAC participants however sparsely used community pharmacists' services, and did not consider the pharmacy as their first or a trusted source for healthcare advice, suggesting less suitability for help seeking support.
Conclusions: Interventions for timely help-seeking for dementia should include steps that bridge the trust gap between BAC people and community pharmacists. Culturally tailored dementia educational interventions for the BAC population and training for community pharmacists on the impact of cultural beliefs on BAC people's help seeking for dementia should be considered.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-03Depression and dementia risk: exploring the impact of cognitive dysfunction during recurrent depression in middle-aged British South Asians: a qualitative study

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Background: Depression is one of the 12 modifiable risk factors that we can target to reduce our risk of dementia and improve brain health. A significant number of people living with depression experience cognitive dysfunction, impacting their memory, attention, and concentration. In some cases, cognitive dysfunction persists even after recovery from depression. This has shown to increase relapse rates, leading to recurrent depression. Some studies have shown depression with cognitive dysfunction to increase the risk of developing dementia. British South Asians are at greater risk of developing both depression and dementia. Thus, it is important to understand their experiences of subjective cognitive dysfunction in depression as a potential preventative measure for dementia.
Aims: This study explored subjective experiences of cognitive dysfunction during recurrent depression in a sample of 12 British South Asians aged between 45 and 60.
Methods: We conducted semi-structured interviews to understand how cognitive dysfunction presented in episodes of depression and what impact this had on quality of life, occupational and psycho-social functioning. Data was analysed using thematic analysis.
Results: Participants described how challenges around attention and concentration resulted in lower quality of social relationships due to not feeling present during interactions and feeling misunderstood, resulting in social isolation (a risk factor for dementia). Depression, coupled with cognitive dysfunction, made it more difficult for participants to engage in enjoyable activities, many of which promote brain health. The emotional, physical, and spiritual impact of cognitive dysfunction was reported across participants as negatively impacting quality of life.
Conclusions: The implementation of cognitive strategies in therapies may support people living with depression and improve symptomatic and functional recovery. Measuring cognition during the treatment of depression may contribute towards our understanding of depression as a risk factor for brain health and dementia.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-04Creating a tool to strengthen nurses' cultural competency with Design Thinking

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Introduction: We aimed to develop a tool that can strengthen the cultural competency of nurses to improve appropriate care for ethnic minorities with dementia and their informal caregivers.
Method: We applied Design Thinking in a participative action research using five phases: 1) Empathise, 2) Define, 3) Ideate, 4) Prototype and 5) Test.
Participants: The Design Thinking Team consisted of key stakeholders comprising healthcare professionals, an informal caregiver with an ethnic minority background, students and the first and second author.
Results: In the Empathise phase, the aim was to understand and list the most urgent problems perceived by nurses and ethnic minorities with dementia in accessing healthcare. Subsequently, the Design Thinking Team defined the problem: “It is difficult to map all those involved in the care for the person with dementia, and to be able to ask the right questions”. The main conditions for the tool were drawn up in the Ideate phase. ‚In the Prototype and Test phase, the tool was developed and tested iteratively within the Design Thinking Team.
Conclusion: We produced a communication tool that may improve cultural competence of healthcare professionals. Further research will focus on the long-term use of the tool through a pilot study to facilitate an understanding of the effect on strengthening the (cultural) competency of healthcare professionals.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-05Co-working with local Caribbean communities to raise dementia awareness and normalise talking about dementia

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Background: Our recent systematic review highlighted that there are complex cultural, religious, and personal reasons that may make African and Caribbean older adults reluctant to seek support from mainstream healthcare professionals when they or their family members begin to experience dementia symptoms. In order to increase dementia awareness and encourage help-seeking behaviour amongst the African and Caribbean community, there was a need to understand what kind of support will be considered helpful by community members.
Methods: The research team, which included a Caribbean co-researcher who is well known in her community, has conducted community group consultation sessions, and delivered 'dementia introductory talks' to local residents by regularly visiting elders' groups for Caribbean people in the East Midlands of the UK. Over 12 months, the research team has consulted over seventy Caribbean community members, a Church leader who has extensively supported the Windrush generation, a local councillor, and five regional charity organisations providing dementia care to local people with dementia.
Results and Conclusion: Responses to our dementia talks varied greatly between the groups. While some groups openly talked about the challenges of caring for their community members with dementia, other groups were reluctant to disclose their personal views on dementia and shared their reservations towards dementia research involvement. Community members highlighted there were very limited culturally appropriate day services available for Caribbean older people. While local charitable organisations stated they are 'inclusive' of all people from all backgrounds, the growing ethnic diversity in the UK means it is becoming increasingly difficult to meet unique cultural needs of different ethnic groups when providing dementia care. Our current ongoing work includes training local elders group facilitators in Cognitive Stimulation Therapy and developing culturally appropriate resources for Caribbean older people as part of ongoing effort to normalise talking about dementia.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-07eHealth interventions for dementia to support ethnic minority groups: scoping review

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This research is conducted within the SPREAD+ consortium as part of the ZonMW DementiaResearch Program, and financially supported by Alzheimer Nederland and Health Holland (WE.32-2022-01)
Background: Technological advancements such as eHealth interventions for dementia can enhance the physical and mental health of the dementia care triad (people with dementia, informal carers, and healthcare professionals). However, it is unclear to which extent eHealth interventions for dementia have taken into account ethnic minorities. Therefore, our aim is to do a literature review of the eHealth interventions for the dementia care triad that have been developed to support ethnic minority groups.
Methods: All types of study design were included in the search. Four different online databases were searched from 2007 until now: PubMed, PsycINFO, Scopus, and Embase. Google Scholar was searched for gray literature. Articles were screened by two independent reviewers to increase the reliability of the results.
Results: After deduplication, 3742 articles were included for abstract and title screening. Forty-nine articles were included for full text screening. Our review identified 32 studies that specifically targeted eHealth interventions for dementia aimed at supporting ethnic minority groups. Most of the research on eHealth interventions for dementia, particularly focusing on ethnic minority groups, has been conducted in the United States and Australia. Chinese immigrants in the United States were the most common target group. Identified eHealth interventions included: websites, apps, email support, and technology-based psychoeducational- and videophone interventions.
Conclusions:A significant wealth of research has been conducted on eHealth for the dementia care triad to support ethnic minority groups. However, an intersectional perspective, which considers the unique impact of intersections of ethnicity, age, gender and class on the needs, strengths, and stressors of people of the dementia care triad, is lacking.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-08Promoting Inclusion: co-design of a guidebook for involving people living with dementia who are part of ethno-racial communities in research

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Objective: The increasing ethno-racial diversity of the populations in many countries means that the diversity of individuals living with dementia is also increasing. However, individuals who participate in dementia research often do not reflect this diversity. An environmental scan of guidance in this area failed to find resources to support researchers in the intersection of dementia, diversity, and research. The objective of this presentation is to describe an initiative that aimed to address this gap by co-designing a Guidebook for researchers and research teams to support them in conducting research with ethno-racial communities, thereby promoting greater inclusion in research.
Methods: Guided by a diverse Steering Committee of people living with dementia, family/friend care partners, providers working with people living with dementia and/or people who are part of ethno-racial communities, and researchers, the Schlegel-UW Research Institute for Aging co-designed a Guidebook for researchers and research teams. Development of the Guidebook included a rapid review of the literature, monthly meetings with the Steering Committee to develop draft content for the Guidebook, and a symposium involving a group of 35 people living with dementia, care partners, providers and researchers to review and provide feedback on the Guidebook using a World Café process.
Findings: The Guidebook is a reflective resource to support researchers and research teams in considering: (1) individual biases, assumptions, and privileges; (2) how to learn about the community the researchers want to work with, including the community's identity, history, and trauma; (3) building relationships and trust with communities; and (4) considerations for the research team and research processes. Information about the development of the Guidebook and insights learned during the co-design process will be shared.
Conclusion: The Guidebook, and insights gained from its development, will help to promote research with ethno-racial communities that is safe and inclusive.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-09Yaad participatory project; exploring memories with South Asian communities to understand the context of family of care for people with dementia

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Introduction: South Asian diaspora in UK experience inequalities in accessing diagnosis and care for dementia and are also underrepresented in research. Our aim was to engage with community groups using participatory research. Memories of home and migration was a starting point and also a way to explore family traditions and cultures of care.
Methods: We engaged community leaders in three cities and facilitated participatory workshops encouraging community members to share evocative memories, make notes and bringing old photos or mementos. Researchers took anonymised observations and invited members and community leaders to focus group discussions.
Findings & Discussion: We invited members of women's groups and yoga groups to workshops, thus the majority of workshop members were women, aged 60 years and older and were of Gujarati or Punjabi ethnicity. Members were attracted by the topic of memories; they may not have attended if it was advertised as a dementia event. While stigma is a challenge, members were comfortable raising questions and discussing dementia. Memories of childhood games and cooking were popular topics, with recollections of childhood in Africa, Malaysia as well as India. Memories of political events and migration could be traumatic, but were also important aspects of personal identity. Members recalled popular culture; films and music, as shared memories and noted changes in communities. Family relationships are changing and sharing memories between generations could enable younger generation to understand the cultural traditions. We have discussed digital communication technology to facilitate social interaction between family members and help care at home. The groups continue to co-design research about technology to support family care.
Yaad workshops indicated that an asset-based approach to memory may be optimal when engaging underserved communities. When aiming to support home care, intergenerational relationships are central and sharing memories can be a way to appreciate cultural differences.

Inclusion and intersectionality - Minority ethnic groups

QOP4. Quick oral presentations - Minority ethnic groups

QOP4-10Intersectional research in dementia care of people with dementia from culturally and linguistically diverse backgrounds: a scoping review

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Background: Preferences are crucial to the daily lives of people living with dementia. Yet, there is a scarcity of data on the preferences of culturally and linguistically diverse individuals, as well as the intricate factors that influence these preferences.
Objective: The goal of this scoping review is to explore the various factors that influence the everyday preferences of individuals with dementia by examining peer-reviewed research and grey literature. This involves identifying and understanding the breadth and depth of evidence available on the complex experiences faced by people with dementia in shaping their everyday choices.
Methods: The eligibility criteria of the scoping review are determined by the PCC framework (P = Population, C = Concept, C = Context). We systematically searched for literature in English, German, and Turkish without any publication date restrictions using MEDLINE, PsycINFO, CINAHL, Scopus, Cochrane Library, Ovid Medline, and Epub. We analyzed the identified intersectional determinants of preferences using inductive content analysis.
Preliminary results: Very limited studies with a focus on the intersectional determinants of preferences, needs, expectations, values or goals of people with dementia from culturally and linguistically diverse group have been found. So far, we have screened 1404 studies and included seven studies from reference lists; hand search is still ongoing. Currently, two themes emerged that were qualitatively different across groups, including (i) culture and gender differences in preferences about caring and formal services, and (ii) language and communication preferences across different cultures.
Conclusion: Recognizing the complex preferences of culturally and linguistically diverse individuals with dementia and understanding the intersectional determinants can enhance the quality of care and satisfaction with the services provided, thereby addressing the need for visibility and support within these underrepresented groups.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-01What matters most in everyday life: empowering the voice of people living with dementia through collaborative research

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Research into the needs and priorities of people with dementia is crucial for developing tailored interventions and support. Conducted in the Netherlands, this interdisciplinary study adopts a sociological approach and cross-European authorship to focus on "everyday life". By using the everyday as an overarching frame to broaden understandings about living with dementia, our previous research has shown that it is possible to look beyond conventional care paradigms and embrace opportunities for social citizenship and meaningful participation to occur. Whilst this wider perspective is important, it is also vital that such developments are consistently informed by the voice, values and experiences of people affected by dementia. In our study we used creative and participatory social research methods with people living with dementia, such as home tour interviews and walking and/or cycling interviews, to gain further insights about their everyday life and what matters most. Six dimensions of what matters most in everyday life were identified through this process, namely: 1) Engaging in meaningful activities, 2) Keeping a sense of connection, 3) Having a sense of belonging, 4) Connecting to self, 5) Adjusting to ongoing changes, and 6) Being open to help and support. Furthermore, our study, and the construction of these dimensions, was supported by a group of co-researchers in the Netherlands living with dementia who call themselves “Brain Power”. The group collaborated with the research team to enrich the data analysis and also contribute towards knowledge dissemination. Each of the six dimensions on the everyday life model holds significant potential to integrate and apply person-centred psychosocial interventions. In the presentation, we will elaborate on this process, the work of “Brain Power” and the development/application of the everyday life model.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-02Supporting autonomy for nursing home residents with dementia: a realist analysis

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Introduction: Being autonomous is important for people with dementia living in nursing homes. Yet, they experience difficulties in being heard as an autonomous person and in expressing their preferences and choices.

Aim: This study aims to uncover how people with dementia, family members and professionals perceive autonomy in daily care and subsequently we aimed to improve autonomy in an action research cycle.
Methods: We performed a realist action study. Four small-scale living units participated. We used interviews and observations to gather data on how autonomy is perceived by family members and professionals. These data were analyzed into hypotheses to enlighten causation between contexts and mechanisms leading to an outcome on autonomy. After choosing and executing an autonomy intervention after six months a second measurement was performed to assess possible effects.
Results: In a situation analysis we initially found 19 hypotheses labelled into four themes: 1. Maximum autonomy support and its boundaries, 2. Organization of daily care processes; 3. Team collaboration and competences and 4. Interaction and matching triangles. Interventions such as: improving autonomy in eating and drinking processes, inviting clients to be present at care meetings, improving autonomy in relating with family members were implemented. Preliminary results of the final measurement show that in spite of strong motivation, implementing and maintaining an autonomy intervention is a challenge for professionals, due to working conditions, daily dilemmas and a high turnover of clients and co-workers. Living and working in a group environment also appeared to be influential.
Conclusion: The results show that supporting autonomy for people with dementia in nursing homes is valued highly but also demonstrate that realizing autonomy depends on a capable, cooperative, sufficiently staffed team. Autonomy interventions are also facilitated by a matching relationship in the triangle, where clients, family and professionals are able to create a trustworthy relationship.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-03Social death of older adults residing in nursing homes in Finland

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Social death refers to situations in which individuals become socially excluded from social interaction or are considered socially insignificant. Social death is about losing roles, relationships, and eventually identity in the eyes of others. When becoming a permanent resident in a nursing home, older adults with severe physical and cognitive disabilities face an increased risk of social death. However, empirical research on social death and its

manifestations in nursing homes are still scarce.
The aim of this study was to investigate the phenomenon of social death by interviewing family members (N=19) of older people living in nursing homes in Finland. A theory-driven thematic analysis of family members' interviews revealed two cross-cutting themes that were linked to social death in nursing homes. We discovered that 1) the transition to a nursing home significantly narrowed the older adults' social environment and 2) dementia seemed to affect all aspects of older adults' social life and social agency negatively. Furthermore, four main mechanisms of social death in nursing homes were 1) losses associated with decline of physical and mental health, 2) loss of social identity, 3) isolation and lack of social connectedness, and 4) lack of quality of care.
It seems that nursing home residents, especially persons living with advanced dementia, still face social death and are not seen as persons who are entitled to social roles and meaningful activities. Thus, there is an urgent need to improve the social connectedness of older adults living with dementia in care facilities.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-05A systematic review of physical performance trajectories in moderate to severe dementia: differences between community and nursing home setting

Selina Kasprzak[1], Charlotte Schmidt[2], George Burchell[2], Sietske Sikkes[2], Erik Scherder[2]
[1]Kennemerhart, [2]

Objectives: The objective of this systematic review was to investigate differences in physical performance trajectories between community-dwelling and nursing home dwelling persons with dementia.
Methods: A literature search without date or language restrictions was performed to identify longitudinal observational and (non-)randomized controlled trials with care-as-usual control groups measuring physical performance in the community setting (CS) or nursing home setting (NHS) amongst ≥65 year old adults living with moderate to severe dementia with at least three month follow-up. PubMed, EMBASE and Web of Science databases were searched. Risk of bias was assessed, and narrative synthesis was undertaken. Differences between baseline and follow-up were converted into percentages per month for each performance-based test, and were compared between settings.

Results: Of 6775 studies, 17 were included covering 78 physical performance measurements: three studies in CS and 13 studies in NHS. Physical performance parameters included upper limb strength, lower limb strength, static balance, dynamic balance, endurance and the Short Physical Performance Battery (SPPB). Of the physical performance measurements, 83% declined, 15% increased and 2% showed no change. More decline was observed in NHS compared to CS for endurance (NHS -4.90%; CS -1.68%) and SPPB (range NHS -1.03% to -2.27; CS -0.69% to -1.55%). In contrast, CS showed more decline compared to NHS in dynamic balance (CS -4.56% ; NHS -3.21%) and flexibility (range CS -9.18% to -21.89%; NHS -1.36% to -4.24%). Lower and upper limb strength showed inconclusive results.
Discussion: Our findings suggest that physical performance declines more in NHS, although this was not found for all physical performance measurements. Diversity in study characteristics and outcome measures, as well as under-representation of studies in the CS hamper interpretation and comparisons between studies. Future research should focus on longitudinal studies with home-dwelling persons with dementia who transition to the nursing home.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-06A Patient journey of older people with dementia in the Netherlands

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Background: In the Netherlands, 70 percent of persons with dementia live at home, with or without support from an informal caregiver. Within the process of dementia, from the early signs of cognitive decline to the end of life, a lot of different professionals are involved in providing formal care and support. The aim of this study was to explore the experiences and needs of caregivers and persons with dementia of formal care and support to improve the patient journey.
Method: The study took place in three phases. In the first phase, the content of the patient journey was outlined in six stages, and semi-structured interviews were conducted with informal carers of persons with dementia and persons with dementia. In the second phase, results of the interviews were discussed with multidisciplinary professionals. In the third phase, professionals worked together on improving: communication, collaboration and

practical support.
Results: We conducted six interviews with informal carers and six interviews with persons with dementia. In total 18 professionals from different healthcare and welfare organizations participated in three workshops. The workshops resulted in practical improvements. Professionals made new agreements on task division and coordination. A website was launched for clients and informal caregivers with information on local facilities and knowledge on dementia. On a regional level, a pilot has started to improve support in emergency situations and support of informal caregivers.
Discussion: A patient journey is a valuable method to pinpoint problems and needs of older persons with dementia and informal caregivers. It provides a foundation for multidisciplinary communication and improvement of coordination and collaboration between professionals. Furthermore, the practical improvements are based on the needs of informal caregivers and persons with dementia.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-07Understanding post diagnostic dementia support through football organisations to provide person-centred, culturally appropriate support for underserved communities

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Newcastle University

Background: There are significant inequalities in the provision of post diagnostic dementia support in the UK, and further inequalities in terms of access. Males from lower socio-economic communities in the UK are traditionally less likely to seek support to manage their health and are at increased risk of isolation. Football (soccer) is a long-established part of culture and heritage, and has historically been a cornerstone of 'working men's culture' in the UK; and as such, football organisations are uniquely placed to provide community support. Increasingly, football organisations are developing dementia support initiatives, but little is known about how widely available this support is and the current models of care and support.
To better understand this emerging provision, and what is different from dementia support services held in traditional settings, this research focuses on identifying current support available and important components of these initiatives to provide person-centred, culturally appropriate support for people living with dementia and their families from underserved

populations.
Methods: For this qualitative study, scoping review methods were used to gain a better understanding of provision of dementia initiatives offered by football organisations in the UK. This included desktop searches of public facing information, contacting organisations for additional information, and attending meetings with leading football and dementia organisations. Data were collated around themes to establish the key components of these initiatives.
Findings: There is considerable variety in the provision of dementia support offered through football clubs in the UK. Nine core components which define these diverse dementia initiatives were identified: activities provided; key personnel involved; intended recipients of the initiative; whether the initiative is dementia specific; location; mode of delivery; regularity of the initiative; funding and costs; and access.
These findings have relevance to other Europe countries and globally, where football is a well-embedded aspect of culture.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-08People with dementia as active participants in pain management: an ethnographich study in nursing homes

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Background: The literature describing pain management in people with dementia living in nursing homes mainly focus on the limitations dementia entails in describing and expressing their own pain. However, people with dementia have resources that could be essential in pain management. Little is known about how healthcare personnel can support the contribution of people with dementia. Our study aimed to explore how people with dementia can be active participants in pain management and contribute in pain management processes.
Methods: We applied an exploratory design with a focused ethnographic approach and collected data through participatory observations. The study setting was a nursing home unit specialized in dementia care in a city in Norway. The study included residents with dementia in moderate to severe stage (n=17) and their formal caregivers (n=12). The data was analyzed inspired by qualitative content analysis.
Results: People with dementia can be active contributors in pain management, if they

receive support from healthcare personnel. The results show how the person with dementia possesses the moment, and healthcare personnel are carriers of continuity. People with dementia and healthcare personnel are dependent on adequate processes of pain management and the right contextual prerequisites. The results were described in relation to how: (1) people with dementia contribute to create and maintain a pain narrative, (2) healthcare personnel support, interpret and integrate the resident's pain expressions in pain management and (3) the nursing home can be a supportive context for pain management. Conclusion: People with dementia have individual resources and strengths of importance for pain management. With support from healthcare personnel, they can be active contributors in pain management processes.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-09Better mealtimes for people living with dementia: working with care homes to share good practice

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People living with dementia are at risk of eating and drinking difficulties. In care homes, this population is often dependent on carers at mealtimes, who provide essential and complex care. At its best, mealtime care is transformational; it can improve quality of life, and reduce hospital admissions. However, evidence has shown a lack of high-quality training on mealtime care for people living with dementia.
In response to this, our project has brought together a group of care home staff, family carers, and health and care professionals to develop a set of good-practice principles in mealtime care for people living with dementia. These principles promote choice, independence, social well-being, safety, and nutrition and hydration. They have informed a training programme which is currently being tested in UK care homes.
At the same time, a small working group is developing an animation to share these key principles quickly and widely. This working group is also drawn from the UK care homes community, and includes residents, carers, nurses, activity co-ordinators, and managers. The group is working with a not-for-profit design company to produce compelling and accessible

multimedia resources, including an animation. Meetings are held in a local care home, and designed to be accessible for all members to attend and participate, regardless of background and experience. The working group will organise online and in-person events to launch the animation in a way that is tailored for care home staff. In this way, we will be able to share good practice in mealtime care for people living with dementia in a timely way that reaches further and communicates more clearly than traditional approaches.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-10Dementia-friendly community centre's make it happen! Social inclusion and participation of people living with dementia

Miriam Groenhof, Anne de Boer
Alzheimer Nederlands

Almost 300.000 people live with dementia in the Netherlands. It is estimated that this number will rise up 420.000 in 2030. 72% of the people living with dementia live at home. For this reason, Alzheimer Nederland invests in dementia-friendly communities. Such communities make social inclusion and participation of people living with dementia possible and have the potential to contribute to the quality of life.
In 2021 we conducted a needs assessment (N=500) among people living with dementia who live at home and their caregivers to identify their interest regarding participating in social activities. We found that 47% preferred to participate in social activities that are for elderly people in general. 32% expressed to prefer social activities that are specifically and only for other people living with dementia and their caregivers. In 2023 we invited 13 locations that provide social activities for elderly in general to participate in an Action Research. These locations tested and co-developed a toolkit ' dementia-friendly community centre's'. Seven guidelines are provided: 1. Integrate dementia in existing policy. 2 Skills training for volunteers. 3. Meaningful activities for people living with and without dementia. 4. Expend your network. 5. Dementia-friendly space and building. 6. Communication strategies to lead people with memory problems or early signs of dementia to their social activities. 7. How to stay dementia-friendly in the future. Furthermore, these locations received a maximum of 5000 euro to fund their needed changes.
A qualitative evaluation showed how all locations were intrinsically motivated to become dementia-friendly, all used the toolkit and made changes to become more dementia-friendly. Our scale up approach started in 2024 and aim to encourage and inspire 800 locations, like

community centre's to become dementia-friendly by 2030.
In this oral presentation we share the insights on the design of the program and first impact results.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-11Involvement of people with mild cognitive impairment in daily decision-making: informal caregivers' perspectives

Elena Garcia Arcelay[1], Sagrario Manzano[2], Mariló Almagro[3], Mircea Balasa[4], Gerard Piñol-Ripoll[5], Mercè Boada[6], Lamberto Landete[7], Eloisa Navarro[8], Inmaculada Abellán[9], Ángel Berbel[10], Beatriz Espejo[11], Miquel Baquero[12], Juan Marín[13], Emilio Franco[14], Jorge Mauriño[15], Pascual Sanchez-Juan[16]
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Background: Understanding the level of involvement of people with mild cognitive impairment (MCI) in making decisions can enable tailoring of caregiver support and resource allocation, encouraging their active participation.
We aimed to examine the involvement of people with MCI in daily decision-making.
Methods: We conducted a non-interventional, cross-sectional study at 19 dementia clinics in collaboration with the Spanish Confederation for Alzheimer's Disease (CEAFA). Individuals providing informal care to people with a diagnosis of MCI according to the National Institute on Aging and the Alzheimer's Association criteria and a Global Deterioration Scale score of 3 were included.
The informant-rated Decision-Making Involvement (DMI) Scale was used to assess involvement in daily decision-making. Total score ranges from 0-45, higher scores indicates a higher level of involvement. A multivariate logistic regression analysis was conducted to identify associated factors among both individuals with MCI and their informal caregivers.
Results: 196 caregivers were included. Mean age (SD) was 63.5 (13.1) years, and 62.8% were female. 68.4% were individuals´ spouses with a mean age of 72.9 (7.0) years and a Mini-Mental State Examination score (IQR) of 26.0 (23.0-27.0).
DMI (SD) mean score was 23.1 (9.8). Patients were most actively involved in decision-making regarding medical care, expenditure choices, and expressing affection, whereas participation in religious or spiritual activities, owning a pet, and determining bedtime were the least engaged in activities.
DMI score positively correlated with MMSE score (rho=0.188, p=0.010) and negatively with age (rho=0.177, p=0.013). Involvement in decision-making was associated with living with their partner (p=0.028), being in a relationship with the patient (p=0.004), and being young (p=0.036) in the multivariate analysis.
Conclusions: According to their informal caregivers, people with MCI had a moderate level of involvement in daily decision-making. Age and living situation were significant factors influencing participation, pointing to the need for tailored caregiver support strategies.

Living with dementia - People living with dementia

QOP5. Quick oral presentations - People with dementia

QOP5-12A new conversation about (the myths of) dementia

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Founded in 2020, the Reimagining Dementia: A Creative Coalition for Justice is bringing together people who share a belief in the power of creativity to positively and humanistically transform the "tragedy narrative" of dementia and to effect individual and social transformation. The Coalition has 1,000 plus members – people living with dementia (PLwD), care partners, activists and advocates, health professionals, artists, academics, etc. – in 44 countries.
Now recognized as a grassroots catalyst for change and a visible "hub" and community of belonging for all, the Coalition's mission is to leverage the resources, experiences and successes of our members and allies in support of transforming the practices and understandings of dementia – at the highest levels possible.
In addition to creating an original song/video, "Let's Reimagine" with artists and members across the world, the Coalition launched Taking It to the Streets in September 2023. The week-long campaign featured dozens of public-facing events, conversations activities that reached thousands globally.
In this conversation with Mary Fridley and Phyllis Fehr, moderated by Tracy Gibbs, participants will learn more about the Coalition, its history and explore these, and other, questions:
How do we turn the loss-focused and harmful myths of dementia on their very wrong heads?
What would it mean to transform our view of diagnosis from that of "defining truth" a starting point for creativity and life?
Is it possible to create environments which support us to express the emotionality of dementia and embrace the uncertainty and the fear of dementia and memory loss?
How can caring people the world over be supported to boldly and broadly reshape the dementia conversation from, as Anne Basting urges, "…the tyranny of memory to the power of imagination"?
And what if promoting joy, creativity, belonging, community and humanity is as curative as anything happening in the laboratory?

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-01Co-designing nature based research with people living with dementia and their care partners



34th Alzheimer Europe Conference
New horizons – Innovating for dementia
Geneva, Switzerland
8-10 October 2024 #34AEC

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Aims: This paper discusses the process and outcomes co-designing nature-based research with people living with dementia and their care partners, first as a pilot project, and then going on to secure external funding from the Canadian Alzheimer Society. This paper contributes to the growing recognition of the importance of inclusive and participatory approaches in the design and conduct of dementia research.
Methods: The initial co-design process, involved a small group of people living with dementia (n=2), care partners (n=2), and a former care partner (n=1). They were involved in all aspects of the design of the pilot project via collaborative sessions to identify the needs, preferences, and aspirations of the participants. Practical exercises, such as visiting potential project nature-based locations together to assess their suitability for people living with dementia and alignment of the aims of the pilot project. Pilot project data collection methods were also agreed together. Based on the participation and ongoing discussion with the original small group, and the additional participants in the pilot project, we worked together to create a research application for funding (successful, commenced March 2024).
Findings: Several key priorities emerged, including the importance of connections to nature and the outdoors, social connections, and accessibility. Insights and learnings were applied to our new and ongoing co-design work with people living with dementia, including tools for group priority setting and ways to ensure participation and understanding.
Conclusion: The value of involving individuals with lived experience in the development and evaluation of nature-based research was immense. Insights gained contribute to the evidence base about applying participatory approaches with people living with dementia. Findings highlight the importance, for people living with dementia and for the research design, of incorporating the perspectives of individuals living with dementia and their care partners, to achieve inclusive research and practice.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-02Involving the public in our pilot study developing a nature-based intervention for people living with dementia: how we did it, what occurred and what we learned



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Introduction: Patient and public involvement (PPI) in dementia research is important, especially in studies developing and testing novel interventions for people living with dementia. Reports and anecdotal information on the experience of PPI from a researcher perspective is scarce, but this information could help inform and inspire future researchers on how to integrate PPI into their research.
Methods: We ran three PPI groups and met with PPI members individually between January 2024 – April 2024 to co-develop a caregiver-led, manualised nature-based intervention for people living with early-moderate stage dementia or mild cognitive impairment, and their caregivers. The PPI included people living with dementia and mild cognitive impairment, family caregivers, dementia nurses and third sector organisations running nature-based activities for people living with dementia. The PPI meetings involved a mix of in-person and virtual (Zoom), group and 1:1 sessions, depending on the person's preference.
Results: We will discuss our experience of recruiting for, setting up and running PPI within our study. We will present how we did this, how the meetings went (including PPI suggestions for what they would like to see in a nature-based intervention) and what we learned.
Discussion: Integrating PPI throughout our pilot study will help to ensure that the study is acceptable, feasible and ultimately useful, for people living with dementia, mild cognitive impairment and caregivers. This is imperative if we want to develop and test an intervention that could potentially be rolled out into services in the future. PPI provides unique and important insights into the running of a study, including but not limited to study design, intervention development, and dissemination of results.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-03The impact of game play on dementia knowledge: a student evaluation of the co-produced dementia inequalities game

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Background: A lack of knowledge about dementia in the health and social care workforce is a recognised barrier to accessing a diagnosis and care. The Dementia Inequalities Game was co-produced with people with personal, professional, and voluntary sector experiences of dementia, and is an educational tool to educate about dementia and associated inequalities and overcome this knowledge gap in the current and future (in training) workforce. The aim of this study was to assess the impact of playing the co-produced Dementia Inequalities Game on knowledge about dementia and associated inequalities in health care and allied health professional students.
Methods: We conducted game play workshops as part of regular teaching in undergraduate and postgraduate courses in psychology, nursing, occupational therapy, physiotherapy, orthoptics, and radiography at one University in the North of England. Data collection commenced in November 2023. Students did not have to partake in the teaching session. Participating students completed a brief before and after knowledge questionnaire about dementia and inequalities. Data were analysed using paired samples t-tests in SPSS.
Findings: Whilst the study is still ongoing, 243 students took part in the game play workshops to date, with 238 providing complete data. Playing the Dementia Inequalities Game resulted in significant improvements in knowledge about dementia ($p<.001$) and dementia inequalities ($p<.001$).
Conclusion: The Dementia Inequalities Game proves to be an effective tool to educate students in health care and allied health care about the topic area. Next steps will include to test the game and its impact in the health, and social care, workforce.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-04Co-research as part of patient and public involvement: NRS neuroprogressive and dementia network partners in research and ENRICH Scotland RICH Voices

Rosalie Ashworth[1], Partner in Research Tbc[2]
[1]NRS Neuroprogressive and Dementia Network, [2]

Co-research is becoming increasingly used as a way to involve people living with dementia in research. Within the NRS Neuroprogressive and Dementia Network is a patient and public involvement group known as Partners in Research. One of the activities that our Partners in Research living with dementia wanted to see was co-research opportunities based on the ideas and experiences they have had. Our presentation will provide background context for Partners in Research before focusing in some of the co-research opportunities designed, developed and co-led by people with lived experience. One area of co-research looks at post-diagnostic information available to people living with dementia and their loved ones. The topic was chosen based on Partners in Research experiences of not having suitable post-diagnostic information, or having very inconsistent access to helpful resources. As a group, we explored the literature available and whether there were restrictions in place for the different types of information e.g. academic access. We explored multiple research designs and looked at how best to answer the research questions set out by the co-research group. The presentation will explore the different research processes, including ethical approvals, before providing an update on whether the co-researchers have got to over the past few months. Finally, the presentation will explore some of the additional challenges of setting up a co-research project within care homes, where people may lack capacity but wish to take part. We will provide an update on getting co-research started within a care home environment, and share learning outcomes for others wishing to complete co-research in care homes with people living with dementia.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-05Inclusion from the start: co-development and application of a priority-setting method for dementia care research

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[1]University of Kent, [2]Person living with dementia, [3]Volunteer supporter for Keith

The voice of people living with dementia (PLwD) is paramount in dementia care research. It is increasingly common for PLwD to be involved in supporting funding applications,

shaping study design, and contributing to dissemination (e.g., Miah et al., 2020). However, PLwD often become involved only after researchers have already determined the overall topic or area of research. While various approaches, tools, and methods have been developed for setting priorities in health and social care research (e.g., Yoshida, 2016), few have been successfully applied in priority-setting work with people living with dementia.
The aim of our priority-setting work was to exclusively amplify the perspectives of PLwD. While the opinions of all stakeholders involved in dementia care are important, there has been a tendency for carer and service provider perspectives to considerably outnumber those of PLwD when research priorities are set (e.g., Kelly et al., 2015). Our work, therefore, included only people living with dementia.
To ensure that priority-setting methods are inclusive and accessible, we adopted a three-step approach. Our work began with a collaboration between a university-based researcher, a co-researcher living with dementia, and their volunteer supporter. This ensured that all aspects of the work were informed by lived experience.
Next, a 'working group' of people living with dementia came together to develop the prioritization approach. This group focused on determining how best to facilitate a larger group of PLwD in setting research priorities for dementia care. Finally, the co-produced approach was used during priority-setting events and included ranking priorities by perceived importance.
In this presentation, we will share both the priority-setting approach co-produced with people living with dementia and the priorities themselves. Additionally, we will discuss our reflections on the collaboration process and share lessons learned that may benefit others considering research priority-setting with PLwD.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-06Dealing with power imbalances in research involving people with dementia: an auto-ethnography protocol

Sascha Bolt[1], Robert Brontsema[2], Femke Muller[3], Glenn Proctor[4], Isabeau van Rompuy[4], Maren Salzwedel[2], Stella Thissen[3], Carolien Smits[5], Marjolein de Vugt[4], Debby Gerritsen[3], Sytse Zuidema[2], Simone de Bruin[6], Gili Yaron[6]
[1]Tilburg University, [2]University Medical Center Groningen, [3]Radboud University Medical Center, [4]Maastricht University, [5]Pharos, [6]Windesheim University of Applied Sciences

Involvement of people living with dementia in research is increasingly recognized as crucial for the relevance and quality of dementia research. The roles of people with dementia in research can encompass being respondents, advisors, or coresearchers. Throughout their interactions within research projects, researchers and people living with dementia may face complexities related to (perceived) power imbalances. Such imbalances may lie in the methodological and ethical domain. We need a better understanding of how researchers handle power imbalances when collaborating with people with dementia. To better understand their experiences, we are currently setting up a study to explore how researchers identify and navigate (perceived) power imbalances in research involving people living with dementia. The study is part of a national research consortium entitled SPREAD+ (Sustainable and PeRsonalisEd Advances in Dementia care). One of the consortium's goals is to stimulate the inclusion of people living with dementia in research. SPREAD+ researchers (six PhDs) are encouraged and trained to involve people living with dementia in their projects. The current study will draw on their experiences to explore the role of power imbalances in dementia research. To this end, the PhDs keep semi-structured diaries to reflect on their interactions with people with dementia and regularly meet to reflect on their experiences. Their diaries and fieldnotes from the reflexive meetings will serve as autoethnographic data for our study. The data will be analyzed using Cardiff's critical-creative hermeneutic data analysis framework. People with dementia advised us on the design of the study. They may also contribute to the analysis, interpretation, and reporting of findings. The study's results will inform the development of a guideline to aid researchers in improving their collaboration with people living with dementia. In our presentation, we will share the study's theoretical background and design protocol, as well as the preliminary findings.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-07Engaging in different ways: contrasting engagement processes to co-develop supports for people living with dementia

Laura Middleton[1], Laura Middleton[1], Carrie McAiney[1], William Heibein[2], Heather Keller[1]
[1]University of Waterloo, [2]

Development and implementation of supports for the health, function, and well-being of people living with dementia is a priority. To ensure supports are meaningful and practical, the engagement of people living with dementia and care partners is essential. This presentation will describe how people living with dementia, care partners, health and social care providers, and researchers were engaged in participatory action research to improve the supports for the health and well-being of people living with dementia. We will contrast the co-development processes used in three projects: the Dementia-Inclusive Choices for Exercise (DICE) project, the Dementia Resources for Eating, Activity, and Meaningful inclusion (DREAM) project, and the Dementia Lifestyle Interventions for Getting Health Together (DELIGHT) project. Each project aimed to engage co-development teams in authentic partnership but how the teams were engaged differed. We engaged participants through in-person workshops, small Zoom meetings, large Zoom meetings with breakout rooms and online polls, and email and telephone co-design processes. Despite diverse engagement processes, co-development participants rated all approaches highly in relation to the principles and enablers of authentic partnership. The presentation will discuss strengths, challenges, and solutions for engaging in each way and suggest contexts for future use. The right approach for engagement likely depends on the goals of the engagement, who is engaged, and where they are located.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-08Scottish Dementia Working Group – Dementia research – We're all in

Wendy Rankin-Smith[1], Kenny Moffat[2], Rynagh Flynn[2]
[1]Alzheimer Scotland, [2]Scottish Dementia Working Group

Alzheimer Scotland's annual winter campaigns aim to raise awareness of dementia and our work, and always feature and are produced in conjunction with people living with dementia and their carers. The 2023 campaign, 'Dementia research - We're all in', focused on the crucial part we can all play in furthering brain health and dementia research. Conveying the idea that research funding is not just an investment in a future where early detection, improved treatments, and perhaps even a cure for dementia become a reality, but in improving the lives of people living with dementia now. It celebrated the idea that everyone has something to contribute to the dementia research landscape, especially those with lived

experience.
A series of short campaign films were made featuring people with a dementia diagnosis, including Scottish Dementia Working Group members, sharing their stories, their aspirations, and their hopes around dementia research, asking the public to get involved in learning, participating, and donating to research. The involvement of people with dementia was unscripted allowing their authentic opinions and involvement in research to stand as the campaign's focus.
People living with dementia shared key dementia research messages:
"Research is not only about medicines and cures, It's about the condition – what causes it, what the risk factors are, understanding how to live well with it, what the opportunities are."
"Traditionally, people with dementia have been written-off. There's always been a focus on the 'end-stage.' But there are thousands of people who are living with the early stages of the condition – and they have valuable contributions to make."
The campaign reached more than 150,000 people over the course of a month and the key messages endure, conveying personal stories and a human touch to encourage support for dementia research, and highlighting "Together we're the change – are you in?".

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-09Evolving public involvement: running our own research project

The Dementia Research Advisory Team[1], Claire Odlum[2]
[1]The Dementia Research Advisory Team / The Alzheimer Society of Ireland, [2]The Alzheimer Society of Ireland

Background: The Dementia Research Advisory Team (DRAT) is a group of people living with dementia and carers/supporters involved in dementia research as co-researchers. The group is supported by The Alzheimer Society of Ireland (ASI). Having worked successfully on projects with external researchers, the DRAT decided to utilise their skills and experience to take on a new challenge: Running Our Own Research Project (RYORP).
The Process: Members of the DRAT met with their UK counterparts, the Dementia Enquirers, to learn further about running their own research project. A topic was decided through a vote. The DRAT employed a Research Assistant to conduct a literature review to identify research gaps and refine their research question. Following training on research methodology, members utilised focus groups and surveys for data collection. They

undertook facilitation skills training, supported by PPI Ignite to prepare for data collection. Focus groups were facilitated by members of the DRAT and surveys were designed and distributed with the support of The ASI. The Research Assistant completed the data analysis, supported and verified by DRAT members. Members focused on developing tangible outputs from the research and have now turned their attention to disseminating their achievements and their findings.
Scope of the presentation: Members of the DRAT will outline their experience of RYORP, highlighting their successes, challenges, lessons learned and dissemination plans. They will also present an overview of their qualitative and quantitative research findings. This presentation will showcase the unique collaboration of family carers / supporters and people living with dementia as they use their lived experience to conduct research authentic to their experience; the impact a diagnosis has on the person who becomes a carer / supporter.

Inclusion and intersectionality - Public involvement in dementia research

QOP6. Quick oral presentations - Public involvement in research

QOP6-10Tools to successfully involve people with dementia in research

Birgit van Ee, Simone de Bruin, Anouk Jansen, Gili Yaron, Franka Bakker, Leontine Groen - van de Ven, Gözde Duran, Geraldine Visser, Leonie Copraij
Windesheim University of Applied Sciences

Good care and support for people with dementia is of great importance, especially given the increasing number of people with dementia and the lack of medical treatment as a cure. Research must also focus on the support that people with dementia and their loved ones need to live well with dementia. In order to properly include their perspectives and interests from the start, studies are ideally designed together with people with dementia. Unfortunately, this is easier said than done.
To investigate how people with dementia can be involved in research to a greater extent, researchers from the Living Well with Dementia research group conducted a literature review and interviewed nine researchers who have experience with involving people with dementia in their own research. In addition, we consulted our advisory board consisting of people with dementia and informal caregivers.
This showed that people with dementia are mainly involved as respondents, but hardly as

co-researchers. The literature and interviews revealed many do's and don'ts regarding approaching people with dementia, obtaining consent for participation, and participating in an interview or observational study. A patient and flexible attitude, building a relationship of trust, and taking into account the needs and possibilities of people with dementia are important. Relatives and healthcare professionals can promote participation, but sometimes act as protective 'gatekeepers', which makes participation difficult. Setting up and actually conducting research together with people with dementia was rare, but seemed possible in some studies.
People with dementia can be important contributors to research. Within applied dementia research, researchers increasingly aim to involve people with dementia and the role of co-researcher is explored. Still, more insight is needed to what extent involvement as fellow-researchers is possible and desirable. Nonetheless, this project offers tools to foster the collaboration with people with dementia in research, in whatever role.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-01E-learning on dementia risk reduction for the general public: a pre-post evaluation study

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Background: There is consistent evidence for the contribution of modifiable risk/protective factors to dementia risk, which offers opportunities for primary prevention. Yet, the majority of the general population seems to be unaware of these opportunities. Online education about dementia risk reduction may be a low-level means to increase knowledge and support self-management of dementia risk. Methods: A pre-post survey study was conducted with community-dwelling individuals who signed up for a free e-learning called “Keep your brain healthy”, that was co-created with Alzheimer Nederland. The e-learning covers seven themes: the brain, physical activity, healthy diet and alcohol consumption, cognitive activity, mental wellbeing including social wellbeing and sleep, cardiovascular health, and making sustainable lifestyle changes. These are delivered week-by-week via email which directs users to a quiz and webpage. Participants completed an online survey before commencing the e-learning, immediately afterwards, and three months later. The survey covered user

experience, knowledge on dementia risk reduction, motivation for health behaviors, and engagement in health behaviors. Results: Of 477 included individuals (mean age 63 ± 12 years, 70.9% female), 339 (71.1%) completed the survey immediately after e-training completion. Engagement with specific themes varied from 71.4% ('Making sustainable changes') to 87.3% ('The brain'). The e-learning scored 8.0/10.0 on average. More individuals became aware of the potential for dementia risk reduction (+14.9%, p<0.0001), and overall knowledge of individual modifiable risk/protective factors increased (Cohen's d=0.464, p<0.0001). Modest improvements in self-reported lifestyle factors were observed, such as adherence to the Mediterranean diet (Cohen's d = 0.178, p=0.0019), cognitive activity levels (Cohen's d=0.268, p<0.0001), and social contact satisfaction (Cohen's d=0.126, p=0.0289). Conclusion: This free e-learning program increased awareness and knowledge of dementia risk reduction and promoted engagement in brain-healthy lifestyles. It can easily be implemented as a stand-alone tool or as part of larger dementia risk reduction initiatives.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-02Characterization of sleep patterns in relation to cardiovascular health in older adults at risk for cognitive decline

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BACKGROUND: Aging is often accompanied by changes in sleep architecture and an increase in the prevalence of insomnia. Lower sleep quality and quantity have both been associated with an increased risk of age-related diseases, such as cardiovascular disease and dementia. However, research has primarily focused on isolated components of sleep in relation these diseases separately, neglecting the exploration of the possible interaction between specific patterns in sleep architecture and cardiovascular health. Therefore, this study aims to identify sleep patterns and examine their association with cardiovascular risk factors in older adults at risk for cognitive decline. METHODS: This study will use the baseline data of the FINGER-NL trial, a two-year multi-centre, randomized, controlled multidomain lifestyle intervention for improving cognitive function in Dutch older adults. Participants aged 60-79 years were classified as at risk for cognitive decline based on the presence of modifiable and unmodifiable dementia risk factors. Sleep quality and quantity were measured using the Pittsburgh Sleep Quality Index, the Insomnia Severity Index and a 7-day sleep diary. Cardiovascular measurements included blood pressure, cholesterol, blood glucose (HbA1c), medication use, lifestyle factors and history of cardiovascular disease. Latent class regression analysis will be used to identify distinct sleep patterns and examine their association with cardiovascular health. RESULTS: The FINGER-NL study population consists of 1210 adults (63.7% female) with a mean age of 67.6 years. Baseline data collection has been completed and results of the proposed analysis will be presented at the conference. DISCUSSION: This study will provide more insight into the relationship between sleep and cardiovascular risk factors in older adults. We hypothesize lower sleep quality and quantity to be associated with higher prevalence of cardiovascular risk factors. Findings may have implications for the development of interventions aimed at improving sleep quality and reducing the risk of age-related diseases within this population.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-03Exploring the influence of lifestyle factors in SuperAgers from the whitehall II cohort

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Background: Cognitive capacities deteriorate with age; however, the pace of decline varies greatly between individuals. While many experience varying levels of cognitive decline, a small group dubbed "SuperAgers" maintain cognitive abilities comparable to those decades

younger. Our understanding of which factors allow SuperAgers to preserve their high cognitive ability remains unknown. It is hypothesised, however, that factors protective against cognitive decline may also help maintain cognitive abilities. Methods: This study uses data from Phases 5 (1997-1999) and 12 (2015-2016) of the Whitehall II cohort, a longitudinal study of British civil servants. SuperAgers were defined as those over 65 at Phase 12 who scored in the top tercile for verbal memory performance in Phase 12 and above the mean for verbal memory at Phase 5. Structural equation modelling will conduct a multivariate statistical analysis investigating the association between engagement in various lifestyle factors (e.g., mental health, physical activity, social engagement, and biomedical factors) in SuperAgers and cognitively normal agers (CN's). Results: The study comprised 1,963 participants (511 females), with 812 meeting the criteria for SuperAgers and 1,156 for CN's. SuperAgers exhibited lower levels of hypertension ($t = 5.13$, $p < .001$), medications ($t = 2.86$, $p = .002$), BMI ($t = 1.79$, $p = .04$), and higher engagement in high social activities ($t = 3.44$, $p < .001$), low social activities ($t = 2.90$, $p = .002$), and vigorous physical activities ($t = -2.00$, $p = .02$). No significant differences were observed between SuperAgers and CN's regarding smoker status, alcohol consumption, sleep duration, mental health, and cardiovascular diseases ($p > .05$). Additional analyses are ongoing and will be completed by the conference date. Conclusions: This study's findings will provide useful insights into the role and significance of various modifiable lifestyle factors in maintaining cognitive function in old age.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-04The association between sleep parameters, cognitive functioning, and markers of structural brain damage: the Maastricht study

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Study objectives: Sleep disturbances are prevalent among older adults and have been recently recognised as a potential risk factor for all-cause cognitive decline and dementia. However, inconsistencies in findings persist due to methodological heterogeneity and the reliance on self-report measures. Therefore, this study aimed to examine the association of

objective and subjective sleep parameters with cognitive functioning and markers of structural brain damage. Methods: This cross-sectional study included 3,343 community-dwelling participants (mean age: 59.6 ± 8.9, 51.0% female) from The Maastricht Study. Sleep duration was objectively estimated using a thigh-worn accelerometer. Subjective continuous sleep (yes/no) was determined through a general questionnaire, and daytime sleepiness was assessed using the Epworth Sleepiness Scale. Cognitive testing was administered across three domains—memory, information processing speed, and executive functioning and attention. Additionally, markers of structural brain damage and cerebral small vessel disease were quantified using 3 Tesla magnetic resonance imaging. Multiple linear and binary logistic regression analyses were conducted, adjusting for demographic, somatic and lifestyle factors. Results: A quadratic association was observed between objective sleep duration and executive functioning and attention ($Bsleep^2$= -0.023, 95% CI= -0.046; -0.000, p= 0.046). However, no significant associations were found for memory, information processing speed and overall cognition (p >0.05). A quadratic association was also observed between objective sleep duration and lower grey matter volume ($Bsleep^2$= -0.012, CI= - 0.024; -0.001, p= 0.040). In contrast, continuous sleep and excessive daytime sleepiness showed no association with cognitive functioning or markers of structural brain damage (p >0.05). Conclusions: Short and long objective sleep durations were associated with poorer executive functioning and attention, as well as reduced grey matter volume among a community-dwelling Dutch population. These findings highlight the potential benefits of optimising sleep strategies to enhance cognition and brain health among older adults.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-05Prediction of cognition using the lifestyle for BRAin health index among middle aged and older adults

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Background: The Lifestyle for BRAin Health (LIBRA) index is developed to assess an individual's room for dementia prevention. The LIBRA index consists of 9 modifiable risk factors and 3 protective factors. Recently, three new additional risk factors (sleep, social activities, hearing loss) were identified. In this study, we investigated the predictive ability

of the LIBRA index with and without the three new risk factors on cognition among adults aged 45 years and older. Methods: Longitudinal data of the Lifelines Cohort Study, a population-based study in the Northern part of the Netherlands was used. Cognition was measured using the Ruff Figural Fluency Test (number of unique designs; range 0-175, with higher score indicating better cognition) at 10 years follow-up. The modifiable risk and protective factors were measured at baseline. Multivariable linear regression models were used to investigate the association between the LIBRA index (modifiable risk factors) and cognition, adjusted for age, sex, and level of education. Results: The mean (SD) cognition at follow-up of the study sample (n=21.393; mean age 52.7 years; 56,9% female) was 57.9 (20.6). The mean (SD) LIBRA index was 0.28 (1.81). There was a negative association between the LIBRA index and cognition (B:-0.44(95%CI:–0.61,–0.27)). LIBRA index adjusted for age, sex and level of education explained 24.0% of the variance, with age, sex, and level of education explaining the largest part (22.8%). Hypertension, diabetes, current smoking, sleep disturbances, and hearing loss were the only risk factors that were negatively associated with cognitive performance at 10 year follow-up. Conclusions: Hypertension, diabetes, current smoking, sleep disturbances, and hearing loss were associated with a lower level of cognition after 10 year follow-up among middle aged and older adults. Differences between groups (age, sex, education) will be explored and presented at the conference.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-07Understanding the experience of hearing loss for people living with lewy body or parkinson's disease dementias

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Aims: Evidence suggests that hearing impairment is common in people living with dementia and hearing loss appears to be a potentially modifiable risk factor for incident dementia. Despite such evidence, little consideration has been given to the experience of hearing loss

in dementia, specifically certain subtypes, and how the occurrence of hearing loss may influence a person's quality of life. Therefore, this study aims to further understand the experience of hearing loss specifically for people living with Dementia with Lewy Bodies and Parkinson's Disease dementia (LBDs). Methods: Qualitative interview study with people living with LBDs and unpaid carers. Interviews were semi-structured and conducted online. Data were analysed using reflexive thematic analysis. Involvement of a multidisciplinary research team and people personally affected by LBDs in the study from conception to analysis strengthened interpretative rigour. Preliminary results: 21 interviews were conducted with people living with LBD (n = 10) and unpaid carers (n = 10). Thematic analysis identified three overarching themes: (1) The ripple effects of hearing loss; (2) Impact of hearing loss correction; and (3) the appropriateness of audiology services. People living with LBDs expressed that the impact of hearing loss extends beyond difficulties with communication and impacts wider LBD symptoms including hallucinations and motor symptoms. While many people with LBDs find audiology tests easy to complete, both carers and people with LBDs expressed that audiology service staff are unaware of how LBDs may impact people and are often not appropriately prepared to support people with LBDs during audiology assessments. Conclusions: These findings may suggest that future research should consider the impact of hearing loss on the plethora of symptoms associated with LBDs. Moreover, while people living with LBDs may find hearing tests easy to conduct audiology staff should receive targeted training to support people with LBDs during assessments.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-08Midlife dementia risk scores and cognition at 90-years

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Background: Midlife dementia risk scores have been shown to predict dementia, but their associations with cognitive function in the oldest-old (90+ year-olds) are not known. To address this, we examined two previously validated dementia risk scores, measured during midlife, with a follow-up period of 48 years. Methods: We had 96 participants from the NONAGINTA study aged 90-97-years and sampled from the population-based Finnish Twin Cohort study participants born in 1922-1933. Risk factors were assessed via postal questionnaires in 1975, 1981, and 1990. We used two previously validated midlife dementia

risk scores, the Cardiovascular Risk Factors, Aging and Dementia (CAIDE) score and educational-occupational score. Self-report CAIDE score consisted of the following variables: age, education, sex, blood pressure, body mass index, cholesterol, and physical activity. Educational-occupational score consisted of age, years of education, work status, complexity of work, physical loading of work and work environment. Telephone-based cognitive assessments in 2021-2023 included semantic fluency (1-minute animal naming) and immediate and delayed recall of a 10-word list learned across three trials. We used linear regression, with total CAIDE score, CAIDE score without education, and educational-occupational score as independent variables. Follow-up time and Apolipoprotein E genotype were included as covariates. We adjusted for family relatedness. Cognition at 90-97 years was our dependent variable. Results: CAIDE score was not associated with any cognitive measures. CAIDE score without education showed a positive association with immediate recall ($p=0.003$), but not with other measures. Higher educational-occupational score was associated with better performance in semantic fluency ($p=0.003$), immediate recall ($p=0.001$) and delayed recall ($p<0.001$). Conclusion: Higher educational-occupational attainment in midlife was associated with better cognition in late old age. Composite measure of midlife cardiovascular risk factors was not associated with cognition in late old age.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-09Evaluation of a public awareness campaign on dementia risk reduction in the Netherlands: a mixed methods study

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Introduction: It is estimated that up to 40% of all dementia cases is attributable to 12 modifiable risk factors. However, the majority of the general public is unaware of the relation between lifestyle and dementia risk. Over the last few years, the public awareness campaign “We are the medicine ourselves” has been conducted in the Netherlands to inform the general public about possibilities to reduce dementia risk. This mixed methods study assessed whether the campaign, conducted in nine municipal health service regions, was effective in reaching middle-aged to older community-dwelling individuals, and the process that has hindered or facilitated implementation.

Methods: Online pre- and post-campaign surveys (N = 10.052) in independent samples of community-dwelling individuals (40-75 years) assessed awareness about dementia risk reduction and knowledge about 12 risk/protective factors. Semi-structured interviews with 21 campaign leaders and stakeholders focused on the campaign message, campaign preparations, positive/negative feedback, engagement of stakeholders, campaign materials, and reactions from the public.
Results: Preliminary results of pre-post campaign surveys showed no population-level difference in awareness of possibilities of dementia risk reduction. The number of correctly identified dementia risk/protective factors was significantly higher post-campaign. Campaign materials were positively rated by campaign leaders, stakeholders, and the public in qualitative interviews. Challenges were identified regarding reaching the younger part of the target group (40-60 years) and active engagement of regional stakeholders. Suggestions for future campaigns included collaborating with (ongoing) health promotion initiatives and deploying ambassadors to reach the underrepresented groups, including people with lower socioeconomic status or migration background.
Discussion: The campaign did not reach a population-level increase of awareness of dementia risk reduction, but knowledge of individual risk/protective factors of dementia increased after the campaign. The campaign design was rated positively. Several practical challenges and recommendations were identified, which will be input for future campaigns in 2025.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-10Adherence as key to success? secondary analysis of the AgeWell.de lifestyle intervention against cognitive decline

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Background: Aim of this study was to investigate how adherence to the components influenced the effectiveness of AgeWell.de as a randomized multi-domain lifestyle intervention against cognitive decline. Focus was on the secondary outcomes quality of life, function in everyday activities, depressiveness and social inclusion. Methods: We analyzed 366 participants of the intervention group of AgeWell.de with an age 60-77 and an increased risk of dementia (CAIDE score ≥9). Adherence was measured for the components nutritional counseling, enhancement of physical and social activity and cognitive training as sum-score of seven time points, answered by a study nurse regarding the achievement of individually set goals. Function of everyday activities (Barthel Index & Amsterdam IADL), depressive symptoms (GDS-15), social inclusion (LNSN) and quality of life (WHOQOL-OLD and EQ-VAS-5) were used as outcomes for generalized linear regression models. Results: Better adherence to nutritional counseling and to physical and social activities was positively associated with health-related quality of life and depressiveness at Follow-up. Furthermore, adherence to physical and social activity improved function in everyday activities. However, the impact of cognitive training remained marginal. No effect was found on social inclusion. Conclusion: Aim of this study was to analyze more in-depth the adherence and its effectiveness. While nutritonal counseling and social activity were already reported to be associated with better cognitive function at follow-up, these results are an important addition. Quality of life and depressiveness are not only associated with cognition, they may also effect the effectiveness of an intervention through feelings of improvement and increased motivation. Furthermore, the results suggest that nutritional counseling and enhancement of physical and social activity, as implemented in AgeWell.de, were effective, yet they have not been able to improve all outcomes the same way. The results help to design future intervention studies in a more targeted and effecive way.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-11DEM-SAFE: co-designing information campaigns to promote brain health and reduce dementia risk in south asian and african Caribbean communities in the UK

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Background: Dementia prevalence is predicted to increase sevenfold among UK minority ethnic communities compared to two-fold in the majority 'white British' population. Modifiable dementia risk factors, such as hypertension and diabetes, are more prevalent among minority ethnic communities, but their knowledge of these factors is limited. Therefore, education and awareness campaigns are needed to encourage healthy lifestyle choices and reduce dementia risk. We aimed to work with South Asian and African-Caribbean communities to co-design culturally targeted interventions to raise awareness of dementia risk. Methods: We conducted eight workshops involving 39 members from South Asian and African-Caribbean backgrounds aged between 30 and 50. Each group identified a risk factor of interest and designed a culturally sensitive public awareness campaign to promote brain health and dementia risk reduction. Workshops were conducted virtually to allow participation from different geographical regions. Findings: Participants believed dementia campaigns should focus on Type 2 diabetes and hypertension as they are major dementia risk factors affecting their communities. However, most participants were not aware that depression and loneliness were associated with dementia risk and were keen to raise awareness of these ‘less known’ risk factors. This will require public and individual-level approaches. The public-level approach would involve working with media influencers and using social media channels to capture community attention. Individual-level behaviour change programmes such as brain health cooking classes, walking clubs within local parks, and board game nights were identified to raise awareness of dementia risks. Utilising associated local community settings with community leaders and/or influencer facilitators would make intervention uptake plausible. Issues around barriers and facilitators were recommended. Conclusion: Awareness of dementia risk factors in South Asian and African Caribbean communities is limited. Co-designing culturally sensitive communication and behaviour change interventions will provide more sustainable brain health campaigns across individual and population levels within the community.

Patient pathways - Brain health and prevention

QOP7. Quick oral presentations - Brain health and prevention

QOP7-12DEM-SAFE: Living well with dementia for South Asian and African Caribbean communities in the UK

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Background: Current forecasts on dementia prevalence suggest that there will be a seven-fold increase in the number of individuals living with dementia from minority ethnic communities. Families affected by dementia from minority ethnic backgrounds report poor knowledge on how to support relatives to live well with dementia. There are currently no culturally sensitive post-diagnostic support interventions for minority ethnic communities, and there is a clear need for education on adopting healthy lifestyles to enable people live well with dementia. Aim: The aim of 'DEM-SAFE – Living well' was to work with South Asian and African Caribbean family carers to co-design an intervention to improve knowledge of living well with dementia through healthy lifestyle changes. Method: We conducted six workshops with 20 carers from South Asian and 10 carers from African Caribbean backgrounds. Results: All carers believed that it was possible to live well with dementia with the right support. An information programme was co-designed to live well with dementia, including a range of topics: healthy diet, exercise, maintaining brain health, managing complex needs, legal and financial advice, and communicating effectively with the person living with dementia. South Asian carers preferred the programme to be delivered in community centres or General Practitioner surgeries and African Caribbean carers preferred churches. South Asian carers preferred health professionals to deliver the programme, whereas African Caribbean carers preferred community leaders from the same ethnic/cultural background as themselves. All carers thought that the programme should be co-delivered by those with lived experience of dementia. Conclusions: This study is the first step in co-designing an information programme for families affected by dementia. The programme will provide families with the knowledge they need to support the person with dementia to live as well as possible. The findings have also highlighted cultural differences in preferences for post diagnostic support.

Living with dementia - Art and dementia

QOP8. Quick oral presentations - Living with dementia

QOP8-01Beyond Culture Box: using arts to train staff and raise awareness of creative dementia care

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Beyond Culture Box aimed to stimulate public interest in dementia through creating new resources, including a touring exhibition (Culture Box Live) that visited two cities in the United Kingdom, and a training course (Lessons from Culture Box) for care home staff and artists. The project took study findings and materials created during a research project (Culture Box) to audiences in publicly accessible arts venues. The aims were to: use the research findings to create novel creative resources to engage new and diverse audiences and stakeholders to stimulate public awareness and interest in dementia, and to develop knowledge exchange and development activities for and with stakeholders (including care staff, third sector organisations, people with lived experience of dementia and their family supporters, and creative practitioners).
Evaluation of the activities involved collecting participant and attendee feedback, alongside reflections from the project team. Ninety visitors attended the exhibitions across both venues. Feedback suggested that it gave them ideas and inspiration to work with those with dementia. A half day training course was successful, with 35 care staff attending. Many enjoyed the interactive nature of the day and the opportunity to meet other people working in the sector. All participants rated the course either 4 or 5 stars (very good or excellent) and 88% would recommend the course to their colleagues. The course provided the participants with inspiration, ideas and connections concerning the role and value of arts and creative activities for people with dementia, alongside an increased confidence in creative and interactive activity provision for people living with dementia. The project demonstrated that arts-based approaches can be effective in raising awareness of dementia with diverse audiences. Staff and artists benefited from the training course, and there is a need to further develop creative training of this type, and to evaluate its impact.

Living with dementia - Art and dementia

QOP8. Quick oral presentations - Living with dementia

QOP8-02DancingtoDementia™: maintaining personhood through dancing

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Malta Dementia Society

Introduction: Over the past three years, the Malta Dementia Society (MDS) have been organizing dancing sessions for persons with dementia facilitated by trained dance facilitators. These sessions seek to bring joy and fun through dancing as well as creating a safe space for expression, memory stimulation, energy, relaxation, movement and positivity, whilst reducing anxiety and loneliness.
Method: Persons with dementia living in different care homes or attending day centres around Malta or living in the community, are provided with dancing sessions that encourage physical exercises such as stretching, muscle movement, coordination as well as cognitive stimulation. Persons with dementia and their family members who can stand are encouraged to dance whilst listening to their preferred Maltese or English songs. Props such as parachute, soft balls, beach balls, balloons, scarves, tinsel, stretch bands are also used.
Findings: Initial evaluation of the DancingtoDementiaTM sessions show that they have been well accepted by persons living with dementia, family caregivers, nursing home management and staff.
Conclusion: Children and parents, husbands and wives and residents and staff have managed to reconnect physically, emotionally, and socially, through the beautiful art of dancing. This presentation will give examples of how this is being achieved from the perspectives of the dance facilitators, family members and residential staff. Moreover, the process of how this one-time funded project has remained sustainable and maintained momentum over the years, will be explained.

Living with dementia - Art and dementia

QOP8. Quick oral presentations - Living with dementia

QOP8-03The Brain Film Fest: a cultural initiative to promote knowledge and awareness of the brain and its disorders, such as Alzheimer's disease

Eva Nebot-Folquer[1], Cristina Maragall-Garrigosa[1], Nina Gramunt-Fombuena[1], Elena Subirà-Roca[1], Naila Fernández-Egea[2], Albert Solé[2]
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The Brain Film Fest (BFF) is an international film festival dedicated to exploring various aspects of the brain, with a significant focus on raising awareness about Alzheimer's disease and dementia, as well as the crucial role of carers. The BFF is an annual event held in Barcelona since 2018, fostered by the Pasqual Maragall Foundation and co-organised with the film producer company Minimal Films.
The festival's mission is to use the audiovisual power of cinema to disseminate and raise

awareness on brain-related topics, while amplifying creators' visibility. It is a platform not only for showcasing films related to the brain, but also for promoting dialogue between science and art and fostering understanding toward persons with neurodegenerative diseases. Central to its objectives is bridging the gap between science and the public, emphasizing relevant topics such as Alzheimer's, dementia, mental health, and artificial intelligence through film screenings, round tables, conferences, discussions, workshops, as well as activities targeting young audiences.
Additionally, the BFF serves as a platform for carers to share their experiences and insights, fostering a sense of community and support. Through its inclusive programming, including sessions tailored for Alzheimer's patients, the festival acknowledges the importance of caring for individuals living with these conditions.
In its last edition, the BFF organized 33 activities (film screenings, roundtables and workshops, among others), attracting more than 4,400 attendees.
In summary, the BFF serves as a significant platform for disseminating scientific knowledge about Alzheimer's and dementia, highlighting the challenges faced by persons diagnosed with the disease and carers, and increasing our understanding to reduce dementia-related stigma and discrimination.

Living with dementia - Stigma and discrimination

QOP8. Quick oral presentations - Living with dementia

QOP8-05The World Alzheimer Report 2024: ADI's global survey on attitudes to dementia - has anything changed since 2019?

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In 2019, ADI conducted the largest global survey on attitudes to dementia to-date. Close to 70,000 people responded from across 155 countries, providing astounding insights on people's attitudes to dementia worldwide. The analysis of the survey was completed by the London School of Economics and Political Science (LSE) and formed the heart of our 2019 World Alzheimer Report. Some key findings of the survey included:

- 85% of people living with dementia reported experiencing discrimination in at least one area of their life

- 62% of healthcare professionals thought dementia is a normal part of ageing
- 1 in 4 people think that there is nothing we can do to prevent dementia

Five years on, ADI and LSE are conducting an updated version of the survey for the 2024 World Alzheimer Report. Translated into over 30 languages, the global survey will focus on four key groups: people living with dementia, caregivers, health and care professionals, and the general public.
In the past five years the world has endured a global pandemic in which people with dementia experienced marked discrimination; several geopolitical conflicts have created humanitarian crises during which people with dementia are often forgotten. Conversely, there are new disease-modifying treatments and new diagnostic technologies coming onto the market. This year, 50 different countries will hold elections - do people feel empowered to make change for dementia through their vote? The updated survey will explore these factors and more.
The Attitudes to Dementia survey will form the central component of the 2024 World Alzheimer Report, due to be launched in September, and will be supplemented by case studies from around the world highlighting best practices and innovation. ADI hopes that the real-world evidence from the global survey will underpin and support advocacy efforts to impact dementia policy in a positive and sustainable way.

Living with dementia - Stigma and discrimination

QOP8. Quick oral presentations - Living with dementia

QOP8-06How people living with dementia using Appreciative Inquiry influenced language and attitudes towards dementia in health workers, caregivers and members of the public

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Whilst accounts of stigma are common, perceptions of a life without stigma for people living with dementia are relatively unheard. Particularly lacking is evidence on how society responds to the anti-stigma perspectives of people living with dementia. This presentation focuses on the results of an Appreciative Inquiry involving a cohort of younger people living with dementia and how their resultant insights were shared with three societal cohorts to gauge their influence on discourse surrounding dementia.
A group of younger people living with dementia in Wales, UK were supported to share

positive experiences, envision a stigma-free society, and craft a concise film encapsulating their discoveries. Thematic analysis revealed four key themes (Belonging, Able, Supported, Dementia Unseen). The film served as a focal point during group discussions involving groups of family members/caregivers, healthcare professionals, and lay people. Positioning theory analysis, aligned to the four themes, was employed to scrutinize any shifts in language regarding dementia following exposure to the film.
Whilst the discourse about dementia altered in all three groups following the film, there were significant differences between them. Family members/caregivers adjusted their discourse to emphasize the significance of finding meaning in individuals' lives, though still centring on the diagnosis. Healthcare workers displayed minimal changes maintaining discourse largely shaped by their experiences with people living with advanced dementia. Lay people were emboldened to align their language with the positive perspectives shared in the film.
Appreciative Inquiry offers a valuable tool for people living with dementia to explore positive experiences and challenge discrimination. Positive narratives have the power to diminish stigma among those with limited exposure to dementia. Further evidence is required to understand how prior experiences influence the impact of anti-stigma campaigns and how positive experiences can be used to reduce embedded discrimination.

Living with dementia - Empowerment and self-management

QOP8. Quick oral presentations - Living with dementia

QOP8-07Improving outcomes for people through future planning

Julia Mackenzie
Alzheimer Scotland

Post Diagnostic Support Link Workers in Edinburgh have been working in partnership with the NHS Long Term Conditions Programme Team in implementing a test of change using Key Information Summaries.
A fundamental element of post diagnostic support delivered by Alzheimer Scotland Link Workers is supporting people living with dementia to consider their future care and future planning. The Link Workers are skilled in enabling conversations with those they support to explore these topics in an inclusive, safe way and at a time that is best for them. The Link Workers assist the person to choose what important information about them and their wishes they want to share with those who may support them in the future. This information is then

shared on their Key Information Summary (KIS). The KIS is held on their GP's computer systems. This information is then available to services with whom they may meet in the future including GP out of hours services, Scottish Ambulance Service and NHS teams who can use the KIS to gain more information.
As the Link Workers have an ongoing relationship with the people they support this ensures that the information held on their KIS is not only important clinical information but also information the person wants people to know about them, their wishes and needs. This information helps inform their future care and leads to better outcomes.
Due to the success of this work in Edinburgh, completion of KIS is now a natural part of Post Diagnostic Support for that team. The Link Workers now also offer to complete KIS for both the person living with dementia and their carers. Various other Health & Social Care Partnerships in Scotland are interested in also developing this work and this is being supported by Focus on Dementia, Healthcare Improvement Scotland.

Living with dementia - Empowerment and self-management

QOP8. Quick oral presentations - Living with dementia

QOP8-08Legal support for power of attorney test of change

Janice Stewart
Alzheimer Scotland

A test of change to provide financial support for arranging Power of Attorney (POA) was launched in 2023 to address the issue of people with dementia being unnecessarily delayed in hospital preventing appropriate alternative community based social care being put in place. With no POA and guardianship orders taking around 8 months to process, delays can be excessive leading to poor outcomes as well as additional costs for families and the NHS. Glasgow Health and Social Care Partnership (HSCP) made funding available to support approximately 200 people living in Glasgow who have a diagnosis of dementia with the legal and registration costs of arranging POA. Alzheimer Scotland post diagnostic support (PDS) service worked in partnership with Glasgow HSCP on this test of change. This service supports approximately 1000 people diagnosed with dementia each year and was well placed to partner this initiative.
An independent evaluation highlights the positive experiences reported by people living with dementia, families, and carers. It demonstrated emotional benefits including a reduction in stress on people with dementia, families and carers and an increased sense of control for

those who arranged POA.
The evaluation also demonstrated the critical role played by PDS link workers in providing an explanation of the benefits of planning for future supported decision making and arranging POA, particularly where individuals and families were unsure how to proceed. This test of change developed good practice, enabling more proactive, confident, and effective engagement with people with dementia, families, and carers on the value of POA. It demonstrated how it can aid supported decision making in the future and deliver outcomes important to them and avoid unnecessary extended stays in hospital if their decision-making capacity became impaired. Glasgow HSCP is considering how to extend this approach and other HSCP's are showing interest in developing similar initiatives.

Living with dementia - Empowerment and self-management

QOP8. Quick oral presentations - Living with dementia

QOP8-09Co-design of a holistic digital health self-management platform for persons living with dementia and their informal carers

Julie Doyle[1], Michael Wilson[2], Orla Moran[2], Siobhan O'Neill[3], Suzanne Smith[2], Jonathan Turner[4], Dympna O'Sullivan[4]
[1]Dundalk Institute of Technology, [2]NetwellCASALA, Dundalk Institute of Technology, [3]Health Service Executive, Our Lady of Lourdes Hospital, [4]Technological University Dublin

Timely intervention and access to adequate services and care are necessary to slow the progression of dementia, to better manage dementia symptoms, to maintain good quality of life for as long as possible and to support informal carers to self-manage their own health while providing effective care. However, people living with dementia and their carers face several challenges along the dementia care pathway, including delayed diagnosis and gaps in services and care. Digital health solutions hold promise to fill these gaps and empower self-management. To better understand the challenges individuals face and how technology might support them, interviews and focus groups were held with 5 persons living with dementia/carer dyads, two additional people living with dementia, 9 additional carers, 15 healthcare professionals and 10 staff from charities. Themes constructed from a thematic analysis included The Impact of Dementia; Gaps in Support for People living with Dementia and their Informal Carers; and Care and Collaboration, with subthemes of the impact of

inadequate supports; reasons for support gaps; lack of formal, integrated care plans; and care strategies. A series of user requirements were derived from the data and personas and empathy maps were developed. These were then brought into a series of iterative co-design workshops with subsets of participants who took part in interviews and focus groups. During co-design workshops, journey maps and storyboards were used to further develop ideas on possible features. Combined with best-practice knowledge on designing digital solutions for people living with dementia and older adults, this resulted in a set of designs for a multi-component digital health platform to support self-management and more holistic person-centred care for both people living with dementia and their carers. Interactive prototypes were then tested in usability sessions with stakeholders.

Living with dementia - Empowerment and self-management

QOP8. Quick oral presentations - Living with dementia

QOP8-10Adaptation of the “Dementia Inequalities Game” to the Irish context

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Introduction: The Dementia Inequalities Game was developed in 2023 by the University of Liverpool, the Lewy Body Dementia Society, and people with lived, caring, professional, and voluntary sector experiences of dementia. The board game raises awareness of dementia including different subtypes, inequalities, and barriers/facilitators experienced by people with dementia and carers while accessing care and support services. Since the game refers to the organisation of dementia care and statistics from the United Kingdom, adaptation of this game will enable its use in Irish care, education, and outreach activities.
Methods: The adaptation process has several steps: 1) a literature review to update the statistics on the game cards; 2) a review and revision of the content of the cards with support from three consultation events conducted with health and social care practitioners, people with memory problems and other dementia symptoms and their supports persons, members of the general public. Each event will last 1-2 hours and will have 8-10 participants. 3) Based on the feedback received, the cards will be revised. 4) The revised (Irish context)

version of the game will be piloted during Dementia Awareness Days in St Brendan's Community Nursing Unit (Loughrea) and the University of Galway. Another pilot event will be held with undergraduate nursing students.
Results: The adaptation process is ongoing. The first two consultation events will be in May and June 2024, with findings available for presentation shortly thereafter.
Discussion: We report on the adaptation of the game to the Irish context, which presents an international example for those interested in adapting the game to their own country and settings. We will extend this work to translate the game into Gaelic (Irish) language to enhance the inclusivity of our approach.
This project is supported by the University of Galway, Age-Friendly College Project.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-01Assessing neuropsychiatric symptoms through speech analysis in early dementia patients

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Introduction: Neuropsychiatric symptoms (NPS) hold prognostic value for cognitive decline in Alzheimer's Disease (AD). However, they are often inadequately addressed in clinical settings. Speech features are impacted in various NPS like depression, anxiety or apathy, even in early cognitive decline. Subtle speech alterations might predict not only cognitive but also behavioral changes in AD, aiding in diagnosis and disease monitoring. This study aimed to examine associations between automatically extracted speech and language features and traditional assessment measurements of NPS. Method: Within the DeepSpa project, speech was recorded from N = 38 patients with Subjective Cognitive Decline, N = 20 patients with Mild Cognitive Impairment and N = 3 dementia patients, who were included in the BioBank Alzheimer Centre Limburg study. Participants answered a narrative

question ("What did you do during your last vacation?"), while NPS were assessed using the Geriatric Depression Scale and the Neuropsychiatric Inventory. Acoustic and linguistic features were automatically extracted. For each feature, a linear regression model was fitted, using age, sex and MMSE as predictors. The model's residuals were used to compute Spearman rank correlations with the clinical scales. Results: Acoustic and linguistic features were associated with agitation, apathy, anxiety and depression. Notably, agitation significantly correlated with Brunet's index (metric of lexical richness) ($r = 0.26$, $p = 0.04$), number of pauses ($r = 0.31$, $p = 0.02$) and mean pitch ($r = -0.36$, $p < 0.001$). Depression significantly correlated with Honore's statistic (metric of lexical richness) ($r = -0.36$, $p < 0.001$), local absolute jitter ($r = 0.35$, $p = 0.01$) and mean local shimmer ($r = 0.23$, $p = 0.07$). Conclusion: Alterations in free speech patterns appear linked to particular NPS, which are considered dementia risk factors and focal points in clinical trials. Utilizing objective assessment tools like speech analysis could improve NPS management and treatment.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-02Understanding the essential components and effectiveness of pre-assessment counselling (PAC) in providing a timely diagnosis according to NHS clinicians

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Dementia continues to be a global health concern owed to its increasing prevalence, and coupled with physical and psychological burden. It is also the most feared diagnosis amongst older adults which may contribute to underdiagnosis. Pre-assessment counselling (PAC) may reduce fear and increase diagnoses when people with suspected cognitive impairment are empowered with choice and feel in control of their diagnosis journey. This study recruited 10 clinicians from an NHS memory clinic in England, UK, and, using semi-structured interviews, sought to understand the mechanisms and effectiveness of PAC. Using reflective thematic analysis, 3 themes were found. 1. The person with dementia (PwD) is central in their diagnosis journey. 2. Candid conversations build strong therapeutic alliances. 3. Patients are more than their diagnoses. Clinicians emphasised the importance of timely diagnosis for the wellbeing of PwD, while also recognising the need for patient-centred and collaborative approaches. Additionally, the study highlighted the significance of

empowering PwD in decision-making processes, fostering resilience through comprehensive support, and addressing stigma through candid conversations to improve diagnostic outcomes and enhance patient engagement in dementia care. The study indicates that PAC is effective in enabling timely diagnoses, but there is a lack of dedicated appointments in NHS Trusts where PwD are empowered to manage their dementia journey and subsequent care.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-03Evaluation of feasibility, added value and satisfaction of remote digital self-assessment for mild cognitive impairment in primary and specialized routine care

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Background: Timely diagnosis of mild cognitive impairment (MCI) in Alzheimer's disease (AD) is crucial for early interventions, but its implementation is often challenging due to the complexity and time burden of required cognitive assessments. Remote unsupervised self-testing of cognition can potentially address this health care challenge. We conducted the to date largest evaluation of feasibility and experienced added value of unsupervised digital remote assessment in primary and specialized health care in Germany. Method: This is a prospective, multi-centric health care research evaluation survey called "re.cogni.ze". Its goal is to evaluate physician satisfaction with a remote digital assessment solution in primary and specialized routine care in Germany. Physicians in different regions of Germany have been recommending the app to approximately 1,000 patients for a 12-week self-assessment of cognition. Last patient out is on 31st January 2024. The primary endpoint is the evaluation of physicians' and patients' overall satisfaction with neotivCare in comparison to neuropsychological questionnaires / standard procedures using a Likert scale. Secondary end points include user-friendliness, qualitative assessment of acceptance, and potential improvements on medical routine services. Result: This is first large-scale assessment of feasibility, satisfaction and experienced added value of remote digital self-assessment of MCI in routine care. The data will be analyzed according to prespecified endpoints after data closure on the 31st January 2024. Conclusion: The study results will provide insights into the feasibility, efficiency, and acceptance of new digital tools for MCI diagnosis in routine care. The re.cogni.ze survey will thus provide proof-of-concept information for the implementation of remote digital cognitive assessment apps for MCI into

medical routine care. 1. Duzel E, et al. BMJ Open 2024;14:e081159. doi:10.1136/bmjopen-2023-081159;

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-04From awareness of cognitive decline to dementia diagnosis: a systematic scoping review of healthcare professionals' considerations and attitudes

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Background: Healthcare professionals (HCPs) are the first point of contact for individuals with health concerns, including potential cognitive decline. As such, they play a crucial role in ensuring timely diagnosis of dementia. However, initiating diagnostic testing is a dynamic and complex process that often involves balancing competing interests. This scoping review aims to provide an overview of HPCs' considerations and attitudes throughout the process from identifying signs of dementia to deciding to initiate diagnostic testing. Methods: PubMed, EMBASE, CINAHL, and PsychINFO databases were systematically searched for qualitative and mixed-methods studies published since 2005. The search covered the concepts: 'dementia', 'considerations and attitudes', 'healthcare professionals', and 'diagnosis'. Two screeners independently conducted title/abstract-screening using AS Review, and full-text screening. Preliminary results: The search yielded 18.241 abstracts. After duplicate removal, 10.279 abstracts were screened, and 79 full-texts were read. In total, 33 studies were included. Most studies involved primary care physicians/general practitioners (n=25), primary care nurses (n=1), or a combination of both (n=7). Preliminary analysis identified that (1) 'Expected outcomes influence HPCs' motivation and timing to establish a diagnosis'; (2) 'The sensitivity of the topic of dementia may lead to reluctance in

starting the conversation/diagnostic testing'; (3) 'The decision-making process is dictated by a wide variety of considerations, challenges, and strategies'. Among these are the difficulty of when, whether, and how to broach the topic; strategies to address or circumnavigate the topic; the balancing act of potential benefits and harms with competing interests; the patient's resistant attitude complicating decision-making; and the key role of family members. Conclusions: Preliminary findings indicate that the main challenges to starting diagnostic testing for dementia are related to the topic's sensitivity, the difficulty of broaching conversations about dementia, and the patient's resistance. The next steps involve evaluating the studies' methodological quality and conducting a comprehensive thematic synthesis.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-05Diagnosing dementia in care homes: supporting increased recognition and diagnosis of dementia in English care homes

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Appropximately 70% of residents living in UK care homes have dementia on admission or develop it during their residence many of whom do not have, or receive, a formal assessment or diagnosis. People living with dementia in care homes are likely to have complex health and care needs so a diagnosis of dementia can inform and support decision-making and care planning even in the advanced stages of the condition. Current memory assessment processes can be burdensome and act as a barrier to diagnosis for many care home residents and so those affected may be excluded from specialist memory assessment services. Creating an abbreviated model can improved outcomes for people living with dementia, their formal and informal carers and ensure more equitable access to a person-centred assessment and create capacity in mainstream memory assessment and treatment services. A quality improvement project in the East of England piloted an abbreviated memory assessment process for people living in care homes in 2021-2022. Over a 6 month period,109 people were assessed with 95 people receiving a formal diagnosis of dementia. Other positive outcomes included the review of medications including antipsychotics, identification of differential diagnosis and referral on to other services if unmet needs were identified. This stimulated NHS England to invest in 14 pilot sites across the country to use

the learning from the initial project and further test the model, this has also stimulated other areas outside the pilots to adopt the model. This session will present an abbreviated memory assessment model for people living with advanced dementia in care homes, data from NHS England funded sites alongside an overview of how the original pilot in the East of England has evolved to become a substantive, award winning Memory Assessment and Treatment Service for Care Homes.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-06User experiences with ADappt: a digital toolkit for personalized prognosis and communication in memory clinics

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Background: ADappt.health is a digital toolkit to support personalized prognosis and communication in memory clinics. We evaluated user experiences and the implementation of ADappt in clinical practice. Methods: We conducted a feasibility study in four Dutch memory clinics. Three neurologists, one geriatrician, two specialized nurses and two junior doctors (12±7yrs experience) recruited 21 patients (69±8yrs, 19%F) and 21 care partners (60±15yrs, 81%F). Professionals were asked to integrate ADappt in their routine, which comprised a 1) topic list, 2) shared decision-making conversation guide, 3) overview of diagnostic tests, and 4) risk calculation tool. Prior to their visit, patients were informed about ADappt-patient tools: 1) educational video-animations, and 2) question prompt list. All participants completed questionnaires on feasibility, usability, and satisfaction after the first

(n=17) and/or disclosure (n=7) consultation. Additionally, EU-FINGERS and LETHE Advisory Boards (comprising citizens, patients, care partners) were consulted on how to better implement the patient tools in clinical practice. Results: Professionals reported good usability (68±14, System Usability Scale, 0-100) and satisfaction (71±10, scale 0-100) with ADappt. They most often used the diagnostic tests tool (16/24(67%) consultations), which they deemed most helpful (3.8±0.4, scale 1-5). Approximately half of patients and care partners reported to be aware of the patient tools (video-animations: n=23/46(50%)); question prompt list: n=30/46(65%)), of whom a majority used (70%) and recommended them (95%). To foster accessibility, Advisory Board members emphasized the importance of: 1) close collaboration between general practitioners and memory clinics, and 2) (re)sending information, e.g., at home, the waiting room, and through various channels, e.g., post, email. Conclusion: Our study highlighted varying stages of implementation readiness of the different tools within ADappt. The diagnostic tests and patient tools are deemed ready. In the Dutch ABOARD-project, we are currently working on sustainable implementation of the patient tools with special attention for accessibility for all patients.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-07Acceptability and key considerations for the implementation of a digital sleep device for dementia risk detection: perspectives of end-users

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Introduction: Digital biomarkers, e.g., digital sleep outcomes, have potential to unobtrusively identify dementia risk in real time by capturing real-world behaviours using digital technologies. Digital sleep outcomes can be captured using an under-mattress sensor, i.e. a digital sleep mat. The InSleep46 study aims to validate outcomes derived from the digital sleep mat as dementia risk markers for future clinical implementation. The aim of this analysis was to understand perspectives of potential end-users on the use of the digital sleep mat as a potential avenue for dementia risk detection. Methods:.31 participants (age: 31-82 years, 11:20 female:male) from Newcastle and London, UK, with personal or caregiving experience related to dementia, took part in focus group workshops. They shared opinions on integrating the sleep mat into their homes, its potential for identifying dementia risk, and

the necessary information for engagement with related services. Inductive thematic analysis was conducted to identify key themes. Results: Five key themes emerged from the data: practical use, acceptability, data accuracy, clinical management, and data management. Briefly, participants highlighted practical considerations for use of the device and indicated it was generally acceptable, "unobtrusive", "easy" and beneficial to wider society. Participants highlighted concerns over potential influences on the accuracy of sleep results (e.g. medication, behaviour of partner). Regarding clinical management, participants referred to five key areas: clinical timepoint for implementation, population of interest, communication of results, post-screening actions and alternative/additional uses of the mat. Discussion around data management related to data access and handling, primarily participants' desire to have access to their own data collected by the device. Discussion: Results suggests that using the digital sleep mat for dementia risk detection is acceptable to those with memory concerns or familial dementia history. End-user perspectives will inform further development, addressing setup practicalities, data analysis covariates, clinical service proposals, and data management.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-08Diagnostic journey of patients with MCI and Alzheimer's disease dementia, and the importance of biomarker testing for timely diagnosis: a real-world survey in Europe

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Objective: To understand the diagnostic journey of patients with mild cognitive impairment (MCI) and Alzheimer's disease (AD) dementia in Europe and specialists' perceptions on utilising biomarker testing in diagnosis.
Methods: Data were drawn from the Adelphi Real World AD Disease Specific Programme™, a cross-sectional survey of primary care physicians (PCPs) and specialists (neurologists / geriatric psychiatrists / geriatricians / psychiatrists / neuropsychiatrists) conducted in France, Germany, Italy, Spain, and the United Kingdom (UK) between December 2022-June 2023. Full data is reported for Germany, Italy, Spain and interim for France and the UK. Analyses were descriptive, summarised as percentages or median

[interquartile range (IQR)]. Sample sizes varied between variables; missing data were not imputed. Results: 193 PCPs and 226 specialists reported data on 2953 patients (1073 with MCI and 1880 with AD dementia). Initially 77% of patients first consulted a PCP, but 74% of these patients were subsequently diagnosed by a specialist. The median time from first consultation with a PCP to specialist diagnosis was 23 [IQR: 12, 48] weeks. Patients diagnosed by specialists had their diagnosis primarily aided by behavioural/cognitive tests (94%), particularly Mini-Mental State Examination (87%), and feedback from patients/relatives (89%). Despite 74% of specialists reporting that biomarker testing will be 'important'/'extremely important' for identifying AD in MCI patients in the future, few patients diagnosed by specialists underwent AD-specific biomarker testing including cerebrospinal fluid (13%) and amyloid positron emission tomography scan (5%). 25% of patients diagnosed by specialists experienced a diagnosis time lag due to lack of access to specialised diagnostic services.
Conclusions: Improved access to specialised diagnostic services is key to accelerate the diagnostic journey of MCI/AD patients and early management. Despite the perceived future importance of biomarker testing in identifying AD in MCI patients, few patients undergo such testing today.
Disclosure: Previously presented at the ISPOR Europe-2023

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-09Characterizing the prodromal phase of frontotemporal dementia using free text analysis of electronic patient files

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Introduction: Changes in neuroimaging and cognition have been demonstrated in prodromal frontotemporal dementia (FTD) on group level, but are not applicable on individual patients, even when clinicians and/or family members observe the first changes in behaviour and cognition. This hampers early differential diagnosis and treatment. The aim of this study is to identify the course of early symptoms in prodromal FTD compared to prodromal Alzheimer's disease (AD) by analyzing free text in electronic patient files and compare this to neuropsychological and MRI data. Methodology: Twenty individuals with genetic FTD, 22 individuals with AD and 20 controls were included. Free text up to four years before

diagnosis from the Alzheimercenter Erasmus MC were thematically analyzed. The identified symptom categories were transformed into percentage of symptoms present within that category and analyzed with non-linear GEE models using time and diagnosis as predictors. Neuropsychological data and radiologists' reports are currently being collected. Results: Thematic analysis of free text revealed eight symptom categories: cognitive, affective, behaviour, language, social functioning, sleep, eating, and somatic. Preliminary analyses revealed that cognitive symptoms are more prevalent in AD at all time points before diagnosis (OR = 0.23 – 0.15, all $p<0.05$), and symptoms related to social functioning from three year before diagnosis onwards (OR = 0.45 – 0.16, all $p<0.05$) compared to FTD. We are currently analyzing both diagnostic groups compared to controls and will present results at the conference. Conclusion: This study identified the course of early symptoms in prodromal FTD as observed by clinicians, compared to prodromal AD. This has important implications for improving early differential diagnosis, and identifying the best time window to start treatment in clinical trials. The next step is to compare both diagnostic groups to controls and results of the free text analysis to standard outcomes for cognition and neuroimaging.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-10Socio-economic and clinical needs and challenges for early detection and progression monitoring of Alzheimer's disease in primary healthcare

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The introduction of blood-based biomarkers for Alzheimer's Disease (AD) diagnosis has facilitated faster, cost-effective, and less invasive clinical pathways [Hampel et al., 2023]. This advancement ranges from early detection of "at-risk" individuals in primary healthcare settings to monitoring treatment response and disease progression in specialized care. Within the scope of the EU-funded 2D-BioPAD project (GA No. 101120706), the authors investigated the socio-economic and clinical requirements and challenges associated with blood-based (specifically plasma) AD diagnostics, primarily in primary healthcare settings. This exploration followed a three-step patient and public involvement and engagement approach. A knowledge base was created through desk research using relevant literature and input from 2D-BioPAD experts. Subsequently, 26 interviews were conducted with Technology Providers (19%), Healthcare Professionals (HCPs) (35%), Decision/Policy Makers (19%), Patients, and Caregivers (27%), refining the initial findings. Additionally, an online survey garnered 96 responses from Biomarker Experts (13.54%), Decision/Policy Makers (13.54%), Primary and Specialized healthcare professionals (HCPs) (30.21%), Patients (11.46%), and Caregivers (31.25%), enriching the knowledge base with insights from a broader audience. The findings underscored the necessity to: 1. Increase public awareness regarding AD and novel diagnostics; 2. Educate HCPs on biomarker-related clinical protocols, starting with primary HCPs; 3. Develop precise, minimally invasive, cost-effective, and accessible point-of-care (PoC) in-vitro diagnostics (IVD) based on reliable biomarkers for use by Primary HCPs; 4. Offer personalized treatment, effective counseling, and referral, including mental health support; 5. Disclose diagnostics' sensitivity, specificity, and reliability based on solid evidence and benchmarks; 6. Provide clear, easily understandable information covering the testing procedure, biomarkers, and post-results next steps; 7. Standardize processes and costs across Europe, with a focus on improved insurance coverage for diagnostics reimbursement. Addressing these diverse needs and challenges is critical for enhancing the AD diagnostic process, ultimately leading to improved outcomes for patients and caregivers.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-11Searching for the ideal centiloid threshold to define amyloid positivity

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Introduction: The Centiloid scale (CL) has been created to harmonize measurements in amyloid PET imaging. Reference cut-off values guarantee uniform decision-making across multicenter research studies. Our study aims to establish CL thresholds based on three independent standards of truths, namely the presence of early or advanced tau pathology, or cognitive decline, within a memory clinic population. We expect different CL threshold for the different purposes and thus different recommendations depending on the context of use. Method: We enrolled 580 subjects who underwent amyloid-PET scans ([18F]florbetapir or [18F]flutemetamol). A subset (n=185) underwent [18F]Flortaucipir-PET within a year. 296 subjects had follow-up cognitive data based on Mini Mental Score Examination. Tau (T) status was visually and semi-quantitatively evaluated from tau-PET and was defined as early tau positivity when only mesial temporal uptake was observed or advanced tau positivity when neocortical uptake was visible. ROC analysis and Youden's Index were applied to estimate optimal CL cutoffs for distinguishing T+ vs T- and stable vs decliner individuals. Results: A cut-off value of 13 CL significantly distinguished stable patients from decliners (AUC=0.677). For T+ patients, CL cut-offs ranging from 14 to 51 significantly differentiated them from T- individuals, depending on the tau deposition regions considered. Specifically, considering both early and advanced tau deposition as T+, a cut-off value of 14 CL was optimal (AUC=0.841). However, when considering only advanced tau deposition as T+, a cut-off of 51 CL was more suitable (AUC=0.913). Conclusion: Different CL thresholds were able to identify distinct biomarker profiles and clinical outcomes. Our findings suggest that a low CL level as threshold for amyloid positivity allows to capture subjects at high risk of decline and with mesial temporal tau deposition. Higher values on the other hand allow identifying with high accuracy the presence of concomitant amyloid and advanced tau pathology.

Patient pathways - Detection and diagnosis

QOP9. Quick oral presentations - Detection and diagnosis

QOP9-12Associations between plasma p-tau217 and neuropsychological test performance in mild cognitive impairment: baseline data of the AI-mind study

Ana Perez[1], Christoffer Hatlestad-Hall[2], Guido M. Giuffré[2], Soraya Alfonsín[2], Timo Saarinen[2], Vebjørn Andersson[2], Antti Kinnunen[2], Claudia

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Background: Developing Alzheimer's disease (AD) involves the accumulation of tau proteins, the degree of which can be approximated from plasma concentrations of phosphorylated tau. The p-tau217 biomarker shows great promise for early AD risk assessment. However, its relationship with cognitive status in mild cognitive impairment (MCI), a precursor stage to AD, remains insufficiently characterised. Objective: To investigate the baseline correlations between plasma levels of p-tau217 and neuropsychological test performance in the AI-Mind cohort of participants with MCI. Methods: The AI-Mind clinical study observes people with MCI over a two-year period with the aim of developing AI-based tools for early dementia risk assessment. The study cohort now comprises more than 1000 participants with MCI across four European countries. Here, we analysed the associations between plasma p-tau217 levels and neuropsychological test performance at the time of the participants' inclusion into the AI-Mind clinical study. Results: Significant correlations were observed between p-tau217 levels and performance in several neuropsychological tests, including tests for verbal and visual memory (RAVLT delayed recall and ROCF delayed recall, respectively), and executive functioning (TMT-B). Higher p-tau217 levels were consistently associated with poorer test performance, with correlation coefficients ranging from 0.21 to 0.25. Interestingly, we observed no interaction effects between age and p-tau217 on test performance. This suggests that age and p-tau217 levels are independently associated with neuropsychological test performance. Conclusions: Baseline data from the AI-Mind study reveal that increased plasma p-tau217 levels are associated with decreased neuropsychological test performance in participants with MCI, independent from age.

SS1. Preparing for new AD treatments (Lilly)

SS1. Preparing for new AD treatments

SS1-01Personal perspectives from a person with early Alzheimer's dementia

Jan Runar Eliassen
EWGPWD

Jan Runar Eliassen is from Norway. He is 50 years old and was diagnosed with Alzheimer's when he was 45 years old. In his presentation, Jan Runar will refer to his experience of receiving a diagnosis of young onset dementia, the impact of the diagnosis on his life and his hopes, expectations and views regarding new medical treatments for Alzheimer's.
Jan Runar is a member of the European Working Group of People with Dementia.

SS1. Preparing for new AD treatments (Lilly)

SS1. Preparing for new AD treatments

SS1-02Moving from research to clinical practice in the treatment of AD

Catherine Mummery
UCL

Currently, our dementia services are primarily community based and insufficiently resourced. Clinical trials environments are highly-regulated, well-resourced and typically manage patients with minimal comorbidities. The arrival of disease modifying therapies, and the beginning of a treatment era in dementia, provides a golden opportunity to reshape services, improve access to diagnostics and reframe conceptualisation of dementia. However, we need to bridge the gap between the real world and clinical trials. I consider some of the questions that arise from considering this, and what we might do to start a journey towards access for all to a biological diagnosis and treatments for dementias.

SS1. Preparing for new AD treatments (Lilly)

SS1. Preparing for new AD treatments

SS1-03How will biomarkers change the game?

Julius Popp
UZH

Biomarkers represent an important tool in the diagnostic and prognostic work-up of dementia diseases. The assessment of biomarkers allows for a more accurate diagnosis, in particular at early disease stages and in cases with “atypical” clinical presentation. An accurate and early diagnosis is essential for a specific counselling and individually tailored treatment. Despite substantial effort in the last decades to implement the use of biomarkers into the clinical routine, a large part of people with dementia still receive no biomarker-supported diagnosis or no formal diagnosis at all. As promising drug therapies emerge, targeting specific brain pathologies, the use of biomarkers to determine the presence of brain pathology and to evaluate the therapy effects on this pathology, becomes even more imperative. Thanks to recent research progress, blood-based biomarkers and other non-invasive markers are expected to become available for clinical practice in the a few years. This trend, along with the approval of new therapies targeting the brain pathologies will likely lead to a much broader utilisation of biomarkers and may accelerate the development of specific and more effective prevention and treatment approaches. While this development will change dementia prevention and care, it will also rise several questions including about the appropriate use, interpretation and counselling that should be provided along with the biomarker results.

SS1. Preparing for new AD treatments (Lilly)

SS1. Preparing for new AD treatments

SS1-04A paradigm shift in clinician-patient communication: embracing patient engagement

Leonie (N.C.) Visser
Amsterdam UMC / UMC Utrecht

The first disease-modifying treatments (DMTs) for Alzheimer’s disease (AD) have been approved in a few countries around the world, marking profound changes in AD-diagnosis and treatment. This brings new challenges in clinician-patient communication.

Initiating DMT for AD is a preference-sensitive decision. Memory clinic clinicians as well as patients and their care partners therefore emphasize the need for shared decision-making (SDM). SDM is not a new concept in memory clinics, yet professionals considered SDM imperative and more complex in the DMT-context, because of the uncertainties regarding beneficial effects, risk of side effects, and the burden of DMT-administration and monitoring.

To enable SDM, clinicians must clearly explain the essential information, including the mechanisms of AD and DMTs, the benefits and the potential negative aspects. Patient engagement is also crucial. Patients and their care partners should express their needs, expectations, and questions and share information on their personal circumstances. This exchange of information is complex, since it includes risks, uncertainty, and sensitive topics. Furthermore, prior knowledge, information needs, and decision control preferences regarding DMTs for AD vary from person to person, highlighting the value of person-centered communication.

To support clinicians, patients and their care partners in having a meaningful conversation about DMT initiation, educational materials and communication tools are needed, developed in co-creation. In addition, we need a paradigm shift towards truly embracing and encouraging patient engagement, both in the preparation for new AD treatments as well as in the future delivery of these treatments.

SS2. DEMPACT

SS2. Enhancing impact: bridging dementia research and practice

SS2-01DEMPACT – bridging dementia research and practice

Minke Kooistra, Marco Blom
Alzheimer Nederland

Scientific research produces lots of new knowledge. Still, professionals in healthcare, welfare, and education are not always aware of the newest information and results from scientific research. The DEMPACT (dementia and impact) consortium wants to increase the use of knowledge and products conducted in research. The consortium is a collaboration between Alzheimer Nederland, Vilans, Movisie, and Pharos.
Background: Currently, one million people in the Netherlands are directly affected by dementia, as a patient (300.000 people living with dementia), informal caregiver (500.000 informal caregivers), neighbour or other. In addition, more than 100.000 professionals work in healthcare and welfare practice. Scientific research produces important knowledge but it is impossible for researchers to reach everyone who could benefit from the newest

knowledge and developments.
Aim: The DEMPACT consortium is assigned to increase the social and scientific impact of ten research consortia professionals, people living with dementia and their cares. The research consortia concern very diverse topics, including causes of dementia, prevention through lifestyle, better diagnosis and better care and support. The DEMPACT consortium is funded by the Dutch ministry of health, welfare and sport's National Dementia Strategy.
Solutions: Improve collaboration between researchers. DEMPACT organises meetings and conference for researchers involved in the consortia. Furthermore we encourage and facilitate them to share data and use FAIR principles. Also, we will set up a DEMPACT academy to train and educate (early stage) researchers.
Connecting research and practice. Only a limited number of practical parties collaborate with researchers. DEMPACT therefore appointed impact managers on several domains: research, healthcare, welfare, education, business, and communication. They will create insight in the needs of several target populations (specific groups of health care professionals, teachers, companies).
Key principles: Value of use, use of existing knowledge infrastructure, targeted replenishment.

SS2. DEMPACT

SS2. Enhancing impact: bridging dementia research and practice

SS2-02DEMPACT – bridging the gap between dementia research and practice Solution 1: improve collaboration between researchers

Carmen Ensink, Minke Kooistra
Alzheimer Nederland

Background: The DEMPACT consortium is dedicated to enhancing the societal and scientific impact of ten research consortia. Achieving scientific impact requires methodologically sound research and strong collaborations among researchers with diverse expertise. Effective dissemination of research results is essential to maximize their scientific impact.

Aim: DEMPACT aims to facilitate and improve the prerequisites for scientific impact and strengthen collaborations between researchers.

Solutions:

1. *DEMPACT Academy*: This talent program targets early career scientists (PhD and postdoc), providing them with a solid foundation for advancing their careers in dementia research. It offers training in a variety of topics from research methodology and patient and public involvement to media training and grant writing. Participants can suggest topics to tailor the program to their needs and gain networking opportunities within the field.
2. *FAIR data sharing and reuse*: DEMPACT aims to create a comprehensive library of metadata from Dutch dementia research datasets in collaboration with HealthRI. Data stewards from the ten research consortia will be invited to join a 'dementia data community' to share best practices and harmonize datasets for retrospective analyses. Additionally, researchers and data stewards will be offered courses to enhance their understanding and practice of FAIR principles.
3. Representative community of people with dementia and informal caregivers: DEMPACT aims to establish a large, representative community of individuals with dementia and their informal caregivers. This community will be accessible to all ten research consortia, allowing researchers to incorporate user experiences into their study designs. Involving this community early in the research process can prevent practical issues that might deter participation and ensure the study's relevance to end users. Special focus will be given to including typically underrepresented groups, such as those with a migration background, lower socioeconomic status, language barriers, and those over 80 years of age.

SS2. DEMPACT

SS2. Enhancing impact: bridging dementia research and practice

SS2-03Bridging the gap between research and healthcare and welfare practice - Solution 2: Strengthening the knowledge position of practicing professionals

Jeroen Vlug[1], Bernice Dekker[2], Minke Kooistra[2]
[1]Movisie, [2]Alzheimer Nederland

Background: The DEMPACT consortium is committed to amplifying the societal and scientific impact of ten research consortia focused on dementia. Achieving meaningful

scientific impact requires methodologically sound research and robust collaboration among researchers with diverse expertise in dementia studies. Additionally, fostering strong alliances at a practical level is essential to ensure successful implementation and enhance the impact on the lives of people with dementia and their caregivers. The consortium is a collaboration between Alzheimer Nederland, Vilans, Movisie, and Pharos.

Aim: DEMPACT aims to connect state-of-the-art dementia research with practitioners in the field. It seeks to enhance the prerequisites for scientific impact and strengthen collaborations between researchers and practitioners.

Solutions:

1. Dementia-Friendly Neighborhoods and Communities: With the dual aging phenomenon, the prevalence of dementia is expected to rise significantly in the coming years. Dementia is not just a healthcare issue but a profound societal challenge. It is crucial to understand what stakeholders in the social domain need to do to create dementia-friendly environments. Through DEMPACT, we bridge the gap between practice and research, equipping stakeholders to foster such environments. Special attention is given to reducing health inequalities and promoting equal opportunities and inclusion.
2. Knowledge Dissemination in Dutch dementia care: The collaborating parties in DEMPACT represent a significant portion of the knowledge infrastructure in Dutch dementia care. A key focus is enhancing knowledge dissemination tailored to the learning styles and needs of recipients. Both physical and digital exchanges of knowledge are vital for reinforcing dementia care. Recent research suggests concrete solutions, such as using accessible meeting places for people with migration backgrounds, implementing technical tools, and adopting social and person-centered approaches to dementia care.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-01Understanding the experiences of individuals with dementia and their caregivers after the Turkey-Syria earthquakes: a qualitative study

Özlem Çiçek Doğan, Seda Güney
Koç University

Objective: This qualitative study delves into the experiences of individuals with dementia and their caregivers following an earthquake. The goal is to uncover the challenges, coping strategies, and support requirements during this period.
Methods: This study involved 10 earthquake survivors who had dementia, along with their caregivers. All participants took part in face-to-face, semi-structured interviews. The data from these interviews was analyzed using the Interpretative Phenomenological Analysis (IPA) method, following the approach described by Smith and Osborne (2007). In the first step, the interview transcripts were read multiple times to identify key themes and notable points in the participants' statements. In the second step, these themes were linked to discover relationships and patterns among them. In the third step, the analysis extended to additional participants to identify similarities and differences in their experiences. Finally, the themes that emerged from the analysis were used to create a detailed report that explained the participants' experiences.
Results: The qualitative analysis yielded four main themes: 1) Adapting to Change and Addressing Unmet Needs, 2) Crisis Care Dilemma: Balancing Concerns for Loved Ones with Dementia, 3) Healthcare Hurdles: Struggles in Access and Support, 4) Navigating Challenges: Recommendations for Well-being.
Conclusions: The study underscores the complex post-earthquake journey for individuals with dementia and their caregivers. Targeted interventions are crucial, including specialized healthcare services and crisis management support. These findings hold significant policy and practice implications, guiding the implementation of interventions that cater to the unique needs of this vulnerable population in the aftermath of earthquakes.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-02Predictors of the cognitive response to multimodal lifestyle interventions for cognitive decline prevention: pooled analysis of four clinical trials

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Welfare, [3]University of Eastern Finland, [4]Karolinska University Hospital, [5]Alzheimer Europe, [6]VU University Medical Center

Background: The upcoming development of Brain Health Services requires an improvement in dementia prevention interventions. Although randomized clinical trials (RCT) have proven that multimodal lifestyle interventions can help prevent cognitive decline, the cognitive benefits are relatively small and vary among individuals and studies. This project aims to identify factors that contribute to positive cognitive responses to multimodal interventions in order to enhance their benefits.
Methods: This is a pooled data analysis from four RCTs conducted in Finland (FINGER study), Sweden Germany, and France (MIND-ADmini study), and Spain (PENSA study and PREDIMED-Plus-Cognition substudy) that explored lifestyle interventions for cognitive decline prevention in older adults. We used retrospective harmonization principles to perform an individual participant data meta-analysis. We examined adherence to the intervention and intervention intensity as predictors of cognitive response, considering also the potential impact of APOE genotype, sociodemographic factors, lifestyle and cardiovascular risk factors, dementia risk scores, and baseline cognitive profiles.
Results: The process of data harmonization was completed as of May 2024. The study involved over 1,000 participants with varying levels of dementia and cardiovascular risk profiles, who underwent diverse lifestyle intervention methods, including multimodal and diet-focused interventions, lasting from 6 months to 3 years. The interventions varied in intensity, with the PENSA Study being high, the FINGER and MIND-ADmini studies being moderate, and the PREDIMED-Plus-Cognition study being low. The full findings of the pooled analysis will be collated by October 2024 to be presented at the current conference.
Conclusions: This study will provide valuable insights into the predictors of cognitive response by consolidating data from four distinct clinical trials, covering a wide range of lifestyle intervention approaches and populations. Findings will contribute to the development of the next generation of precision prevention interventions for cognitive decline.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-03The predictive value of social cognition assessment over and above neuroimaging for 1-year functional outcomes in behavioral variant frontotemporal dementia

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Aim: Behavioral variant frontotemporal dementia (bvFTD) is characterized by prominent socioemotional deficits that negatively impact various aspects of daily living. This study aims to identify the socioemotional predictors of functional status at 1-year follow-up and examine whether socioemotional assessment provides additional predictive value for clinical outcomes beyond neuroimaging data among individuals with bvFTD.
Methods: A total of 78 patients with bvFTD were assessed at baseline with a comprehensive battery of socioemotional functioning involving face-to-face tests and informant-based measures. Regression modeling was performed to identify the strongest socioemotional predictors of functional outcomes (Functional Activities Questionnaire, FAQ) at 1-year-follow-up. In a subset of 57 patients with available baseline structural magnetic resonance imaging (MRI) data, the volumes of functional networks particularly vulnerable in bvFTD, including the semantic-appraisal network, salience network, default-mode network, and frontoparietal network, were obtained by summing regions of interest derived from voxel-based morphometry of atrophy. Multilevel regressions were performed to compare the predictive value of social cognition measures above 1) demographics/severity and 2) neuroimaging data.
Results: Neuropsychological tests assessing social perspective taking and social norm knowledge appeared to be the most robust socioemotional predictors of FAQ at the 1-year-follow-up assessment ($p<0.05$). Structural MRI data alone accounted for 29.02% of the variance in FAQ outcome, but increased to 47.88% when social cognition measures were included in the model.
Discussion: This study highlights the significant contribution of quantifying social cognition, particularly theory of mind and social semantics, in order to predict which bvFTD patients will quickly develop adverse functional outcomes. Socioemotional assessment can capture unique aspects of disease progression and functional decline not fully captured by structural MRI alone.
Conclusions: The integration of socioemotional assessments in clinical practice with bvFTD can significantly enhance clinicians' prognostic accuracy for functional outcomes, thus informing refined treatment strategies for these individuals.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-04Modified Cued Recall test for the diagnosis of dementia of the Alzheimer's type in a Greek population of adults with Down syndrome: a validation study

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Introduction: Alzheimer's disease is significantly prevalent among older adults with Down syndrome (DS). Identifying DS individuals affected by the condition has been proven challenging due to preexisting intellectual disabilities. The aim of the present research study was to examine the capability of the Greek version of the modified Cued Recall Test (mCRT) to discriminate between healthy participants and those presenting dementia of the Alzheimer's type.
Method: This was a cross-sectional multicenter study. 53 participants were included in the initial sample. After a series of both neuropsychological testing and questionnaires completed by participants' supporters, two main groups were formed: a) cognitively healthy and b)cognitively impaired.
Results: Strong negative correlations were detected between age and ID level and participants' total scores on the task ($p < 0.01$ and $p = 0.013$ respectively). Individuals in the lower level of ID were not able to complete the assessment and their data was therefore excluded from further analysis. Statistically significant differences were found between the diagnostic groups and their performance both at immediate and delayed recall ($p < 0.001$, Mann-Whitney U-test) indicating that cognitively intact participants produced higher total scores and that the tool is able to discriminate between healthy and cognitively impaired individuals.

Conclusion: Results suggest that detecting AD symptomatology in DS individuals using the mCRT is possible and are consistent with those reported in previous research studies . Further research is indispensable to validate the Greek version of the mCRT so as to provide quality services and assistance to this unique but overlooked population and their supporters.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-05The role of risk factors in development of cognitive disorders and cognitive decline in the Czech Republic and the Netherlands: comparative SHARE prospective study

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Aim: There's a scarcity of knowledge regarding dementia risk factors in Czechia, leaving uncertainty about whether the positive trends observed in Western studies apply there. This study aims to explore the connection between dementia risk factors and its incidence in Czechia, shedding light on the role each factor plays and compare those to the Netherlands – country representing Western counterparts.
Method: The survival analysis utilizing Cox regression is based on data from Survey on Health, Ageing and Retirement in Europe (SHARE) a multidisciplinary, cross-national study. In both countries participants were included in the study in case they fulfilled following criteria: age of entry to the study 65 and higher, participation at least in two waves of SHARE, at least two measurements of cognitive functions. For the primary analysis, dementia was defined using adapted Lang-Weir classification (LW) utilizing available SHARE cognitive measures: immediate and delayed recall with including instrumental activities of daily living (IADL).
Results: Based on our preliminary results age (HR: 1.12, 95%CI: 1.09-1.14), lower education (HR: 1.64, 95%CI: 1.26-2.12), physical inactivity (HR: 2.1, 95%: 1.63-2.72), diabetes (HR: 1.71, 95%CI: 1.35-2.17) and depression (HR: 1.47, 95CI: 1.17-1.85) play the role of important risk factor in the dementia incidence. Similar results could be observed in the sample from the Netherlands.
Conclusion: This study represents a crucial step toward filling the knowledge gap regarding dementia risk factors in Czechia from the perspective of Dutch counterpart. The identified

risk factors underscore the need for public health initiatives aimed at mitigating these factors to potentially reduce the incidence of dementia and improve the overall cognitive health of the population. Possible explanation of observed trends will be discussed.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-06The effect of cognitive stimulation therapy on apathy, loneliness, anxiety and activities of daily living in elderly individuals diagnosed with Alzheimer's

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This study was conducted to determine the effect of Cognitive Stimulation Therapy (CST) on apathy, loneliness, anxiety and activities of daily living of individuals with Alzheimer's disease. The study was conducted in Gaziantep Moral House between January 2023 and January 2024 in a randomized controlled experimental model. Prior to CST, Standardized Mini Mental Test was applied to the intervention and control groups to determine the cognitive levels of the individuals and randomization was performed. A total of 52 individuals comprising 26 intervention and 26 control groups were included in the study and constituted the sample of the study. Introductory Information Form, Apathy Assessment Scale (AAS), Geriatric Anxiety Scale (GAS), UCLA Loneliness Scale Short Form (UCLA-SF) and Functional Impairment in Dementia Scale (DAD) were used in the study. CST was administered to the intervention group twice a week in 14 sessions. It was found that the individuals in the intervention and control groups had high levels of apathy and loneliness, and moderate levels of anxiety and daily living skills in pre-test. After the intervention, it was found that the mean scores of the intervention group were significantly lower than those of the control group. In intragroup comparisons, it was determined that there was a significant difference between the pre-test and follow-up test of the post-test scores of the individuals in the intervention group after the CST application between the pre-test and follow-up test, and between the post-test and pre-test of the DAD. In line with the results of this study, CST was found to be effective in reducing apathy, loneliness and anxiety levels of Alzheimer's patients and increasing their daily living skills. It is recommended that the

use of CST should be expanded in the field of psychiatric nursing and health professionals working in the field of elderly health.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-07Risk factors for dementia among patients in memory clinic

Nina Stopar, Andreja Špeh, Anja Mrhar, Milica Gregorič Kramberger

Background and aim: Theoretically, we can prevent or delay dementia development in 40% of cases by addressing potential risk factors throughout life. This study aims to examine the prevalence of these factors among individuals visiting a memory clinic. Method: This ongoing study started in October 2023 in Centre of Cognitive Impairments in Ljubljana. Each patient received a questionnaire during the visit at clinic, which they filled out themselves or with help of family member. Data was analysed using a descriptive method. Until end of February 2024 we collected 103 surveys. Results: The average age of participants was 77,8 years (min 51, max 92). 55,3% (n=57) were women. Average education is 11,7 years. They are most often from Central Slovenian region (64,1%). MMSE median 23, mean 21,6. Hearing problem have 39 people (37,9%), but only 9 of them regularly use a hearing aid. 8,7% (n=9) participants had a head injury with loss of consciousness. Antihypertensive drugs are taken by 58,2% (n=60). In 53,4% of the participants SBP was >140 mmHg measured in sitting position (n=55). Alcohol is consumed by 31,1% of the participants (n=32), they drink average 2,3 units weekly. Obesity is presented in 16,5% (n=17). 62,1% (n=64) are engaged in less intensive sports activity and 25,2% (n=26) in medium to high intensity sports. 24 participants (23,3%) have diabetes, almost all diabetics take medication (21 or 87,5%). 30,1% (n=31) are being treated for depression. 21,4% (n=22) are live alone, but most of them can always count on someone's help when they need it (86,4%). 6,8% (n=7) are smoker, 64,1% (n=66) never smoked. Conclusion: The low regular use of hearing aids and the prevalence of hypertension stand out among participants. Other risk factors were not notably prevalent. Data collection for sample representativeness is ongoing.



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Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-08An innovative online educational program on Neurodegenerative Genetic Counseling developed in Greece, Germany, Belgium, Spain and Turkey

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Introduction: Nowadays, with the rising prevalence of neurodegenerative diseases (ND) and the accessibility of genetic testing, it is expected that there would be a greater need for high-quality genetic information on ND, most likely provided in the form of genetic counseling (GC) from qualified healthcare professionals (HCP).
Objectives: The GECONEU project developed an online Course focusing on GC on ND for University students and healthcare professionals. This project's main goals and central impact were to support people, caregivers, and society to better understand the aims of genetic testing and the usefulness of GC.
Results: The three primary outcomes of this initiative are as follows: 1. ¨Transnational Implementation Guidelines for GC in ND¨ focused on GC intervention steps. This result combined different GC protocols as well as a quantitative survey on families of people with ND (PwND), and qualitative research on experts in the field; 2. “An innovative online course on GC in ND” that can be part of the curriculum of Higher Education Institutions (HEI); 3. “A digital Guideline handbook” that helps HEIs and other care organizations to implement the training, including also proposals and directions on how to extend the knowledge on GC. This result was based on extensive testing of the teaching material and

the course in pilots in 5 different countries.
Discussion: Genetic testing for ND has become more significant in personalized treatment and disease risk reduction during the past 20 years, particularly for healthy people with a family history of ND. By including the families of PwND in the development of the educational course, this project offered the chance to consider all the components of a suitable training program for society, thereby increasing their visibility and raising their genetics knowledge.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-09The meanings of the life story of a person living with dementia and their tendency to "wander"-the narrative perspective of Polish caregivers

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Objectives: The aim of the study was to observe the connections that carers see between the tendency to wander and the earlier history of life of people with dementia.
Material and methods: 15 home carers participated in a structured interview with a psychologist. A frequency and qualitative analysis of their statements was carried out in terms of information on the life history of a person living with dementia and the contexts in which they most often wander.
Results: Carers often pointed out the tendency to carry out many household chores during previous activities seeing it as a certain influence on the current need to wander (6 interviews). 7 carers pointed to previous frequent use of allotments and walks as important leisure activities. 2 highlighted a desire to return and 5 interviewees did not include information on the life history of the person living with dementia in their narrative at all.
Conclusion: Carers of people living with dementia largely link their wandering tendencies to their life history and the activities they have often carried out in the past. Looking at the most common themes such as the fulfillment of household chores and the need to be in green spaces, it seems reasonable to seek to engage people living with dementia in different household activities or elements of them (adapted to the stage of the illness) and to allow the use of safe, enclosed green spaces that allow for independent mobility.

Dementia researchers of the future: Innovative approaches to dementia

SS3. Dementia researchers of the future

SS3-10The effect of individual characteristics on the level of nutrition related knowledge: exploratory study for older adults across levels of cognitive impairment

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Background: Healthy eating patterns, such as the Mediterranean diet, are recognised for their role in preventing cognitive decline and dementia. Nutrition-related knowledge (NRK) and its different domains significantly influence dietary behaviour. Therefore, understanding the state of NRK and how it varies across different levels of cognitive impairment is crucial for the development of effective interventions. This study aims to investigate the impact of individual characteristics on NRK among older adults in Slovenia, across different levels of cognitive impairment.
Methods: This study, conducted between November 2022 and May 2023, involved 164 dementia-free older adults who lived at home, did not require assistance with eating and did not follow a medical diet. The data was collected using a structured questionnaire containing information on NRK and socio-demographic characteristics. Two levels of cognitive impairment were defined using the Dementia Screening Interview (AD8). Linear mixed models were used to examine the impact of potential individual characteristics on NRK, with scores and domains presented in standardised values.
Results: The sample had a mean age of 66.7 ± 8.2 years, with 73.8% (n=121) being women. The mean AD8 score was 1.1 ± 2.2, with 46 individuals (28.0%) having an AD8 score of 2 or more, indicating susceptibility to cognitive impairment. In this group, NRK was lower (-0.27 ± 1.03, p=0.012). Factors positively associated with NRK included nutrition-related attitude (p=0.002) and the number of chronic diseases present (p=0.001). Inadequate knowledge of nutrient sources was the primary cause of lower NRK in those at high risk of cognitive impairment.
Conclusion: The study underscores inadequate knowledge of nutrient sources as a significant factor in lower NRK. Policy makers should prioritize accessible interventions to promote a healthy diet by providing comprehensive information on nutrient sources. Further

research is necessary to better understand the dietary behavior of individuals at risk of dementia.

SS4. Gates Ventures

SS4. European platforms advancing dementia detection, diagnosis and care

SS4-02The European Platform for Neurodegenerative Disease (EPND)

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Aim: Biomarker discovery, development, and validation rely on large-scale analyses of high-quality samples and data. However, data and sample discovery, access, and sharing are often hindered by silos limiting collaboration, as well as by complex requirements for secure, legal, and ethical sharing. The European Platform for Neurodegenerative Diseases (EPND) project was established to address these challenges. In this presentation, we will provide an overview of EPND's design and the achievements from the project's first years.

Methods: EPND is a multidisciplinary consortium of 29 partners with expertise in data discovery, ethical, legal, and regulatory aspects of data sharing, biomarker studies, stakeholder engagement, and sustainability. EPND leverages an existing data platform developed by the Alzheimer's Disease Data Initiative (ADDI), allowing the platform to connect to a global network of datasets. The project is funded by the Innovative Medicines Initiative (IMI, grant agreement number 101034344) and is a 5-year project that began on November 1, 2022 (EPND.org).

Results: In the first three years, the design of the data platform has been finalized. We completed a white paper on the ethical, legal, and regulatory aspects of data and sample sharing. We developed standardized operational procedures for sample selection, biobanking, and data harmonization. The project engaged over 80 cohorts, providing access to data from more than 250,000 patients' clinical data and samples. We conducted studies on ATN biomarkers, complement factors, and proteomic analyses with multiple assays in plasma and CSF from 350 patients with Alzheimer's disease, Parkinson's disease, and Lewy body dementia. This dataset will me made available for access requests through the platform.

Conclusion: We have established a multidisciplinary consortium to accelerate biomarker discovery and validation, supporting the development of diagnostics and disease-modifying therapies for Alzheimer's disease and other neurodegenerative diseases.

SS4. Gates Ventures

SS4. European platforms advancing dementia detection, diagnosis and care

SS4-03Solving the AD-RIDDLE: a flexible, scalable platform for personalised dementia prevention and care

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Preventing Alzheimer`s disease (AD) dementia is a global priority. The slow, gradual progression of AD neuropathology from asymptomatic to early symptomatic stages provides the opportunity for early intervention to prevent/delay dementia onset. Major progress on early, accurate AD detection, as well as encouraging results from multidomain preventive clinical trials and single-domain, disease-modifying drugs trials, pave the way to define validated and scalable therapeutic solutions across the AD continuum. To this end, the Real-World Implementation, Deployment, and Validation of Early Detection Tools and Lifestyle Enhancement (AD-RIDDLE) project, supported by the EU Innovative Health Initiative (IHI) public-private partnership and UK Research and Innovation (UKRI), aims to develop, test, and deploy a modular toolbox platform that can reduce existing barriers to the timely detection, and therapeutic approaches in AD, thus accelerating AD innovation. By focusing on health system and health worker practices, AD-RIDDLE seeks to improve and smooth AD management at and between each key step of the clinical pathway and across the disease continuum, from at-risk asymptomatic stages to early symptomatic ones. This includes innovation and improvement in AD awareness, risk reduction and prevention, detection, diagnosis, and intervention. The AD-RIDDLE interdisciplinary consortium includes 24 partners from academia, healthcare system, industry, regulatory bodies, non-profit organizations. The aim is to develop and test the AD-RIDDLE toolbox platform and its components individually and in combination in six European countries. Expected results from this cross-sectoral research collaboration include tools for earlier detection and

accurate diagnosis of AD; validated, non-invasive novel digital cognitive and blood-based biomarkers; and improved access to individualized preventative interventions, including multimodal interventions combining pharmacological (symptomatic/disease-modifying therapies) and non-pharmacological components. Therapeutic approaches will be tailored for diverse populations, within the framework of precision medicine. Overall, AD-RIDDLE toolbox platform will advance management of AD, improving outcomes for patients and their families, and reducing costs.

SS6. Mederic

SS6. Digital devices and psychosocial interventions: challenges and issues

SS6Digital devices and psychosocial interventions: challenges and issues

Christine Tabuenca[1], Nigel Hullah[2], Alain Bérard[1], Maribel Pino[3], Jérémy Kozick Rigaux[4]
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Psychosocial interventions are essential to maintaining and/or improving cognitive, psychological, social and physical functioning and quality of life of people with dementia. A growing number of digital devices are used to provide psychosocial interventions, such as computers, tablets, virtual reality, augmented reality, robots, online sessions… Aside from the innovative aspect and the "wow" effect, it's important to understand these devices and what they can contribute to supporting people living with dementia and their carers. The aim of this symposium is to provide an overview of the digital devices used in the implementation of psychosocial interventions and to discuss the challenges and obstacles to their use.

A flash survey has been launched between July and September 2024 among professionals to find out what type of digital devices they use for which psychosocial interventions, the added value of these devices, the difficulties encountered, training and feedback from people living with dementia and carers.

The results of the flash survey will be presented and discussed by the speakers, with concrete examples provided. A better understanding of the interest of digital devices for psychosocial interventions will enable better use and understanding for professionals, patients and carers.

SS8. Longitude Prize on Dementia

SS8. New dementia assistive technologies to transform lives: Presenting the innovators of the Longitude Prize on Dementia

SS8New dementia assistive technologies to transform lives: Presenting the innovators of the Longitude Prize on Dementia

Fiona Carragher
Alzheimer's Society

On the week commencing the 7th October 2024, Challenge Works, Alzheimer's Society and Innovate UK will publicly announce the five Finalist innovator teams of the Longitude Prize on Dementia. The Longitude Prize on Dementia is a £4 million pound challenge prize programme to drive the creation of personalised, technology-based tools that are co-created with people living with the early stages of dementia, helping them live independently for longer. The Longitude Prize on Dementia is funded by Alzheimer's Society, the UK's leading dementia charity, and Innovate UK and delivered by Challenge Works.

On Thursday 10th October - as part of the 34th Alzheimer Europe conference "New horizons – Innovating for dementia" - a panel session will take place to showcase the prize Finalists and the innovative assistive technologies they are developing. These innovations aim to empower people living with dementia to overcome daily challenges and lead independent, fulfilling lives.

The session will also highlight the impact of the Longitude Prize on Dementia, emphasizing the pivotal role of Alzheimer's Society, Innovate UK, and Challenge Works in driving and supporting impactful innovations through the prize.

The panel discussion will include the participation of Fiona Carragher, Director of Research and Influencing at Alzheimer's Society UK, and a representative from each of the five Finalist innovator teams.

SS9. Essity

SS9. Support for care giving relatives in continence care

SS9Support for care giving relatives in continence care

Nicole Huige[1], Paul Dennis[1], Matthijs Pouwels[1], Paul van Houten[2], Trevor Salomon[2]
[1]Essity, [2]

For persons with dementia, going to the toilet on time and changing incontinence absorbent products, can become a real challenge. Care giving relatives will try to help as much as they can, but situations can become increasingly complicated over time.
If inadequate solutions for this care process are provided, additional work and stress can be the consequence.
Therefore, it is so important that a person with dementia who experiences challenges in going to the toilet, gets a good assessment of the toileting & containment care needs, so solutions can be sought for both the person with dementia and the care giving relative.
Analyzing a person's voiding pattern with the help of digital health technology can be the first step, followed by a care plan consisting of toileting times and the right protection for in between the toilet visits. This all seems logical but is unfortunately not yet happening a lot.
Let us together move the needle on getting attention for this multiple times a day activity, and secure relevant provisions/support in national dementia strategies. These provisions should especially support self-management for as long as possible for the person with dementia and when this is no longer possible, support care giving relatives to make an easy and efficient delivery of this care.
Paul van Houten, specialist elderly care will share expert knowledge on the relation between dementia and incontinence.
Trevor Salomon, Care giving relative, will share his experience with the increasing challenges in this multiple times a day activity.
Matthijs Pouwels, Essity Senior Product specialist iQ, will take us through the latest developments in digital health technology for continence care, showing results from studies from practice.
The session will be moderated by Paul Dennis, Global Brand Communications Manager at Essity.