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Plenary presentations

PL1. Round-table discussion: Dementia in a changing world

ROCHFORD-BRENNAN Helen (Ireland), POSSENTI Mario (Italy), COMAS-HERRERA Adelina (United Kingdom), STEUKERS Lennert (Belgium)

The COVID-19 pandemic has caused disruption to all aspects of life across the world, as measures aimed at slowing the spread of the virus (social distancing, lockdown, closing of places of work etc.) have interrupted normal interactions and ways of working.

Many people with dementia, in particular, found their routines disrupted and often lacked cognitive stimulation, felt lonely and anxious, feared being abandoned and were at risk of depression. Alzheimer associations and care services needed to adapt to continue to provide much needed information, support and care to people with dementia and their carers. For researchers working in laboratory and clinical settings, a multitude of overlapping issues (furloughing or redeployment of staff, closure of services etc.) resulted in research being put on hold.

In this symposium, we will discuss how pandemic has changed the dementia landscape. We will find out from Helen Rochford-Brennan, the chairperson of the European Working Group of People with Dementia, Mario Possenti, General Secretary of Federazione Alzheimer Italia, Adelina Comas-Herrera, curator of LTCcovid.org, a website on the impacts of COVID-19 long-term care and Lennert Steukers, Associate Director at Janssen and Project Lead for the IMI project Neuronet, how the COVID-19 pandemic has affected people with dementia, Alzheimer’s associations, the long-term care sector and dementia research. We will further explore how they have adapted to the situation and which of the adaptations and changes they wish to keep in a post-pandemic world.

PL2. Diagnosis and medical management

PL2.1. Improving the diagnosis of neurocognitive disorders: implementing the recommendations of the 2nd European Joint Action on Dementia

KROLAK-SALMON Pierre, LEPERRE Armelle, CARTZ-PIVER Leslie, FOUGERE Bertrand
Franche

As we are still facing major breaks regarding the diagnosis of neurocognitive disorders (NCD) in Europe, the 2nd European Joint Action “Act on dementia” dedicated its first workpackage on evidence from literature/workshops and innovating program conception aiming at promoting a “timely” diagnosis. The major breaks that arose thanks to literature, workshops and surveys were centered on the misunderstanding by the General Practitioners (GPs) of the main benefits of the diagnosis as compared to the risks, and a lack of clear and shared diagnosis strategy involving primary and secondary care. The resources dedicated to detection and diagnosis represented an important issue.

A comprehensive strategy has been proposed to better convince the general population and the professionals, especially from primary care, to detect earlier the main diseases inducing a NCD. This approach considered 1- reviewing and sharing the benefits of a timely diagnosis 2- building a clear hierarchized and personalized diagnosis strategy 3- testing the feasibility and efficacy of a new “antistigma” and diagnosis training program dedicated to the GPs 4- testing the feasibility and efficacy of an advanced practice nurse detection program and 5- testing the feasibility and efficacy of telemedicine for diagnosis of NCD in nursing homes.

The main results of this full strategy will be presented, as well as the tracks that may be explored to better consider new diagnosis engines across Europe.

PL2.2. Ethical issues linked to the disclosure of diagnosis

RICHARD Edo
Radboud University medical Centre, Netherlands

There is general consensus that a timely diagnosis of dementia is pivotal -- but what is timely? The increasing availability of biomarker tests has led to new research criteria including new disease entities such as ‘preclinical’ or ‘prodromal’ Alzheimer’s Disease. This suggests that an ever-earlier diagnosis is not only possible, but may also be desirable. Arguments in favour of an early diagnosis include autonomy, ‘the right to know’. and planning of the future. But are early diagnoses sufficiently reliable for prognostication and future planning? And is an early diagnosis desirable for a disease for which there is no treatment? If the answer to these two questions is no, one could argue that an early diagnosis has no clinical utility. Arguments suggesting to reconsider the strive for an early diagnosis are the potential overmedicalization of mild memory impairment, and the potential harmful psychological effects of receiving an early diagnosis and the stigma that may accompany this diagnosis. Ethical principles, relevant facts such as the diagnostic and prognostic accuracy of tests and considered moral judgements
should all be taken into account when weighing the arguments for an early diagnosis. This process is highly dependent on the context and personal wishes and needs of each individual patient.

**PL2.3. The pharmacological treatment of Alzheimer’s disease. What have we learned in the past years?**

LOVESTONE Simon
Janssen, United Kingdom

All drug development is difficult, but finding therapies for Alzheimer’s disease is particularly so. There are many reasons for this—the brain is probably the least understood organ in the body, the disease is inherently complicated and doing clinical trials is challenging in this population. Add to this, there is a long period when the disease is active but there are few if any symptoms. Despite these challenges, the scientific field has made huge progress—in our understanding of the disease, in producing potential therapeutics and in doing clinical trials. So far however, these trials have not produced a disease modifying drug. What have we learned from this experience and how can we use this to get to the point where we do actually have a drug. I will review the progress the field has made and suggest that we need to have a more diverse approach to therapies, we need to conduct trials more precisely targeted to the right people and we need to do more efficient trials with earlier decision making. All these proposals are actually underway and all the evidence suggests that so long as investment by companies and by governments together with charities continue, it is only a matter of time before we see therapies that should delay onset or progression of disease.

**PL2.4. Medical management issues in dementia. The new recommendations of the European Academy of Neurology**

WALDEMAR Gunhild
Danish Dementia Research Centre, Copenhagen University Hospital, Rigshospitalet, Denmark

People with dementia often have other medical conditions. Some conditions occur at a higher risk in persons with dementia (such as epilepsy, psychotic symptoms), while other (such as pain and diabetes) may be causally unrelated co-morbidities. Potentially life threatening, and often associated with significant worsening of cognitive performance and quality of life, medical conditions need special attention and care in persons with dementia.

Therefore, the European Academy of Neurology (EAN) Scientific Panel on Dementia established a multidisciplinary task force, who recently developed a new guideline for medical doctors on medical management issues in dementia. The following topics were selected for the guideline: systematic medical follow-up, vascular risk factors in dementia, pain in dementia, use of antipsychotics in dementia and epilepsy in dementia.

While revealing a lack of research-based evidence in certain areas of interest, the guideline provides useful guidance for clinicians.

**PL3: Building dementia-inclusive societies**

**PL3.1. Public involvement in dementia research: developing an approach with the European Working Group of People with Dementia?**

GOVE Dianne, DIAZ Ana
Alzheimer Europe, Luxembourg

Since its establishment in 2012 during Alzheimer Europe’s annual conference in Vienna, the European Working Group of People with Dementia (EWGPWD) has been contributing towards dementia research within the framework of Public Involvement (PI). The group’s approach to PI is the result of a collaboration between different members of the EWGPWD, Alzheimer Europe staff and several researchers from different research disciplines. Members of the EWGPWD have contributed towards a position paper on PI, also in collaboration with INTERDEM, a follow-up article commenting on their experience of PI in dementia research and a report on the promotion of inclusive research (in relation to PI and to being a research participant).

In the first part of this presentation, I will describe the origin of the group, how it has evolved, Alzheimer Europe’s rationale for having the group and the kinds of activities the EWGPWD has been involved in. I will explain how the group’s approach to PI is constantly being improved and adapted, in keeping with the changing dynamics of the group and the recent pandemic situation. In the second part of the presentation, I will briefly address the issues of diversity and training/mutual learning in the context of PI and with reference to the philosophy and experience of the EWGPWD.

**PL3.2. Promoting dementia-inclusive hospitals – the experience of the German Alzheimer’s association**

JANSEN Sabine
Deutsche Alzheimer Gesellschaft e.V., Germany
Since many years the German Alzheimer Association (DAlzG) is lobbying for dementia-inclusive hospitals. By 1.6 Mio people with dementia in the country there are about 23,000 people with dementia in hospitals each day (Bickel et al, 2019). Caregivers have complained repeatedly about difficult situations in hospitals by using the helpline of DAlzG.

Over the years creative projects were developed in hospitals in cooperation with Alzheimer Associations. They adress the education of staff, the involvement of family caregivers, support by volunteers and more. Unfortunately, these ideas have not reached every hospital and are implemented only partially. On 1rst of July 2020 the German National Dementia Strategy was adopted by governement and provides measures to improve the situation in the future hopefully.

**PL3.3. Making Dutch society more dementia friendly**

**HOOGENDAM Jacqueline**

Ministry of Health, Welfare and Sport, Netherlands

In 2013 started the Dutch dementia friendly programme ‘Samen Dementievriendelijk’, part of the Deltaplan for Dementia (2013-2020). This programme was successful. The set goal on number of dementia friends was reached months before the planned end date of the programme, December 2020. The programme developed specific training different branches of businesses as well.

With the development of the National Dementia Strategy 2021-2030, we wanted to go beyond the ‘traditional’ dementia friends. Not just a focus on compensating for disability, but also facilitate the use of abilities: Dementia Friendly 2.0. Empowerment of persons with dementia, stimulating them to have meaningful activities, participate in society.

**PL3.4. The Neighbourhoods and Dementia Study: reflections and directions**

**KEADY John**

University of Manchester, United Kingdom

This keynote presentation will provide an overview of the findings of the five year [2014-2019] ESRC/NHHR ‘Neighbourhoods and dementia study’ that was coordinated by The University of Manchester in the UK. The Neighbourhoods study was funded under the first UK Prime Minister’s Challenge on Dementia. Two of the overarching aims of the Neighbourhoods study were to:

- Explore, test and innovate the role of the neighbourhood in the everyday lives of people with dementia and their carers; and
- Develop an international understanding on the place and meaning of neighbourhoods in the everyday lives of people with dementia and their carers.

The Neighbourhoods study comprised of eight separate but inter-linked work programmes (WP), namely:

- people with dementia undertaking their own neighbourhoods-level research (WP1; University of Manchester lead);
- the uses of large data sets to establish national neighbourhood profiles (WP2; University of Manchester lead);
- the development of a core outcome set about what matters most to people with dementia at home (WP3; Lancaster University lead);
- the use of participatory social research methods to view the neighbourhood as it is experienced by people with dementia (WP4; Stirling and Salford Universities co-leads);
- acute hospital care and staff training (WP5; Lancaster University lead);
- the developed of an app for use in everyday life for couples (WP6; Linköping University at Norrköping lead);
- the meaning of neighbourhood for people who are Deaf (BSL users) with dementia (WP7; University of Manchester lead);
- staff and person with dementia well-being (WP8; University of Manchester lead).

Four PhD students were also attached to the Neighbourhoods study and all have successfully graduated. The Chief Investigator will undertake the presentation and will highlight areas of value and interest to the dementia studies field, including the importance of developing more inclusive research methodologies and the involvement of people living with dementia in research.

**PL4. From research and innovation to clinical and care practice**

**PL4.1. Latest trends in the prevalence of dementia – are prevention messages having an effect?**

**BRAYNE Carol**

University of Cambridge, United Kingdom

There are major influences on our health within societies across the globe that are related to individual risk for dementia. This talk will provide a reflection on what we understand about the epidemiology of dementia at present, how and why this might be changing along with what societal responses are most powerful in their ability to change risk for future generations. This will draw on evidence accrued in population studies over the last decades and also reflect on the role of research in policy and advocacy.

**PL4.2 An interprofessional intervention in dementia education**

**KURZ Alexander, PFAEFFEL Lea**

Technical University of Munich, School of Medicine, Munich; Germany
The quality of care for people with dementia and their family caregivers falls short of international standards in many countries of South Eastern Europe. Specifically, there is a lack of dementia-related knowledge and skills among health and social care professionals, insufficient cooperation and coordination between occupations, and shortage of dementia-related facilities and services such as day care centres or specialised nursing home units. Education of occupational groups is considered to be key for improving dementia care and enhancing the quality of life of people with dementia and their carers (Mehrabian et al. 2019*).

In 2018, dementia experts from ten South Eastern European countries teamed up with entrepreneurs and policy makers to launch an educational and skill-building intervention that addresses all professions involved in dementia care including physicians, psychologists, nurses, social workers, occupational therapists, speech and language therapists, physical therapists and pharmacists.

The intervention is novel in providing a joint knowledge base and a set of shared values in terms of a person-centred and holistic approach in dementia care. The programme complements existing or emerging national dementia strategies in the target countries. It is delivered to professionals in a blended-learning format which includes face-to-face workshops and a multi-media online platform. The development of the educational intervention and its evaluation in pilot actions in four countries is co-funded by the European INTERREG-Danube Transnational Programme from 2018 to 2021. The intervention is currently available in five languages (English, Bulgarian, Slovenian, Slovakian, Romanian).

Dialogue with patient organisations and the policy level is currently ongoing in order to disseminate and sustain the intervention. We see the intervention’s activities as a contribution to “Building Bridges” between people, professions and countries.


**PL4.3. Assistive Technologies - the role of social robotics in dementia**

CASEY Dympna
National University of Ireland Galway, Ireland

Assistive technologies may be defined as any piece of technology used to enhance or optimise functional capabilities. This brief presentation focuses on social assistive robots as an example of assistive technologies used in dementia care. The use of social robots which focus on improving the psychological status and overall, wellbeing of end users will be explored particularly in the context of reducing loneliness and isolation for people with dementia. These social robots include for example PARO and MARIO. Evidence of the impact and benefits of social robots will be explored. The estimated number of people over 60 increases to over 2 billion people by 2050, and because the incidence of dementia is correlated with increased longevity, it is projected that the number of people with dementia will increase to 82 million by 2030 and 152 million by 2050. Simultaneously social and health care workers are reducing. Currently in Europe there are 3.5 workers for every person aged over 65 and this is set to fall to 2.4 in 2030. These changes place new pressures on all aspects of live but on older people in particular. Robotic technology may be considered an alternative option to fill this void in the labour market, yet this hurls its own challenges. Advances in robotic technology lead to more advanced hardware and software capabilities and technical capacity, throwing up further ethical challenges regarding the design of social robots. It is imperative therefore that as we look to the future use of social robots in dementia that we ensure that safeguards and codes of responsible conduct surrounding the development and use of robotic technologies are in place.

**PL4.4. The neurodegeneration portfolio of the Innovative Medicines Initiative – from project results to sustainable assets**

DÍAZ Carlos1, PLA Sandra1, COLL Nina1, GEORGES Jean2, BRADSHAW Angela2, BOUVY Jacoline3, O’ROURKE Diana3, PRADIER Laurent4, RINALDI Manuela5, STEUKERS Lennert6

1Synapse, 2Alzheimer Europe, 3NICE, 4Sanofi, 5Janssen

NEURONET is the Innovative Medicines Initiative (IMI) Coordination and Support Action (CSA) aiming to support and better integrate projects in the growing IMI Neurodegenerative Disorders (ND) portfolio. Its primary objective is to establish an efficient platform to drive synergy and collaboration across IMI ND projects, multiplying their impact, enhancing their visibility and facilitating coordination with related initiatives both in Europe and globally.

As the current pandemic is showing, overcoming fragmentation is fundamental for modern science. NEURONET has been conceived as an eminently operational, pragmatic and agile instrument that will analyse information, assets and needs from the various ND initiatives to accelerate the development and implementation of novel therapeutics across Europe. NEURONET is developing a platform that, on the one hand, facilitates interactions between IMI ND projects and provides management support to the whole programme, and, on the other hand, maps and assesses their scientific impact and their intellectual and technological contributions to boost cross-communication.
Moreover, NEURONET emphasises four areas where synergy is critical: data sharing, privacy and ethics, regulatory interactions, and long-term sustainability. Additionally, through a Knowledge Base, NEURONET helps showcase the diversity and wealth of assets developed by the different projects, helping devise strategies that can help to improve the chances of successful uptake of results.

As a dynamic, efficient and ‘just-in-time’ action, NEURONET aspires to become a blueprint for other portfolios that do not fully catalyse on the huge resources mobilised by individual projects, which often work as silos. By creating structures that help create common direction and harness the power of the different projects towards jointly beneficial outcomes, NEURONET ultimately aims to fuel scientific progress and collaboration to positively impact the lives of the millions of people who live with neurodegenerative diseases in Europe and worldwide.

PL5. Round table discussion: Maintaining dementia as a European priority

CARRILLO Maria1, CHISHOLM Dan2, DAHL Nils3, SCERRI Charles4, TAMSMA Nicoline5

1Alzheimer’s Association, USA, 2World Health Organization – European Region, 3Ministry of Health, Germany, 4Malta Dementia Society, Malta, 5European Commission

The past decade has seen some important advances as regards the recognition of dementia as a public health priority at the national, European and global level.

The number of countries with national dementia strategies has increased significantly and the European Union health programme dedicated two Joint Actions (ALCOVE and Act on Dementia) with national health ministry officials to identify good practices and promote their implementation on such diverse issues as the prevalence of dementia, advance care planning, timely diagnosis, post-diagnostic support, residential care, crisis management and care coordination, and dementia-friendly initiatives.

In parallel, dementia research was prioritised at a European level thanks to increased funding via Horizon2020, the Innovative Medicines Initiative (IMI) and the Joint Programme for Neurodegenerative Diseases Research (JPND).

The G8 Dementia Declaration of 2013 set out ambitious aims for the global community to increase research funding and develop a co-ordinated international research action plan with the stated ambition to identify a cure or a disease-modifying therapy for dementia by 2025. In 2017, the World Health Organisation launched its “Global Plan of Action on the Public Health Response to Dementia 2017-2025” which was followed by the development of the Global Dementia Observatory.

In this symposium, we will review key achievements over the past years, identify how the COVID-19 pandemic has impacted progress and discuss actions and priorities to ensure dementia is maintained as a European priority. We will be discussing this with the audience and our eminent speakers: Maria Carrillo from the US Alzheimer’s Association, Dan Chisholm from WHO/Europe. Nils Dahl from the German Ministry of Health, Charles Scerri, the National Focal Point on Dementia from Malta and Vice-Chairperson of Alzheimer Europe and Nicoline Tamsma from the Health Directorate General of the European Commission.
Special symposia

SS1. My second new life: adapting after COVID-19

Members of the European Working of Group of People with Dementia will be giving a series of short speeches on the topic of the impact of the current pandemic on their lives. This will cover their experiences and reflections on how the confinement and other current measures (such as social isolation) have impacted their lives. It will emphasise some of the positive aspects of the confinement, but also the negative effects on their disease, independence and quality of life. Speakers will also refer to the way they are coping with this new life. A few of the members will talk about their experience of being in hospital or visiting a relative in hospital during this time. There will be time at the end of the session for questions and comments from the audience.

The presenters will be: Helen Rochford-Brennan (Ireland), Angela Pototschnigg (Austria), Bernd Heise (Germany), Stefan Eriksson (Sweden), Carol Hargreaves (Scotland, UK), Nina Baláčková (Czech Republic), Tomaž Gržinič (Slovenia), Idalina Aguiar (Portugal) and Geert van Laer (Belgium).

This special symposium is organised by the European Working Group of People with Dementia.

SS2. Lessons from COVID-19 for AD health system readiness

Alzheimer’s disease (AD) is a progressive neurodegenerative disease which places a tremendous burden on individuals, caregivers, families and society. While there are currently no approved treatments that can change the course of the disease, there is need for health systems to prepare, ensuring new medical advances can be available to people living with AD when they do become available.

The response to the COVID-19 pandemic offers important lessons for health system readiness for Alzheimer’s disease (AD) in Europe. Across countries, the COVID-19 pandemic has clearly shown that without the right measures in place, even highly-resourced healthcare systems can become rapidly overwhelmed by an unpredictable healthcare crisis that affects a large population. The COVID-19 pandemic illustrates the importance of analysing robust data correctly and responding quickly to changing scenarios by using healthcare resources effectively and efficiently. Specifically, the AD community itself has been directly affected by the prevailing COVID-19 situation as individuals are often considered at higher risk of mortality and morbidity. This highlights the fragility of the current approaches to diagnosis, treatment and care for people living with AD.

The number of people with AD is growing, and as illustrated by the COVID-19 pandemic, action needs to be taken now to prepare health systems for the future rising demand from patients and their families as new diagnostic and treatment innovations emerge. An expert panel will share their perspectives on and experiences of the lessons to be learned from COVID-19 for AD health system readiness. To better understand the challenges and opportunities, the panel will explore a range of topics, from healthcare access and service coverage, capacity constraints, the respective roles of primary and specialist care, and how to ensure medical innovation can support a patient-centred care model in AD.

SS3. Dementia and COVID-19

SS3.1. Dementia care in times of COVID-19: telemedicine care at Memory Clinic, Fundació ACE Barcelona

Background: Fundació ACE, Barcelona Alzheimer Treatment & Research Center, is a non-profit organization, providing care based on a holistic health care model to persons with cognitive disorders or dementia and their families since 1996 in Barcelona, Spain. To ensure continuity of care amidst the COVID-19 pandemic has represented a major challenge to our institution.

Objective: To share our experience adapting face to face model of care to telemedicine during the COVID pandemic

Methods: Detail the sequence of events and actions undertaken within Fundació ACE Memory Clinic to swiftly adapt to telemedicine consultations. Characterize individuals under follow-up by the Memory Unit

1Roche, 2University of South California, 3Alzheimer Europe, 4Alzheimer's Disease International, 5CHU Toulouse

LANMAN Lydia1, MATTKE Soeren2, HOLMERova Iva3, LYNCH Chris4, SOTO Maria5, TRABER Martin1

1Roche, 2University of South California, 3Alzheimer Europe, 4Alzheimer's Disease International, 5CHU Toulouse
from 2017 to 2019 and compare the number of weekly visits in 2020 performed before and after lockdown was imposed. Present the evolution of videoconference visits’ adoption and the neurologist and neuropsicologist evaluation protocol adaptation.

Results: The total number of individuals being actively followed by Fundació ACE Memory Unit grew from 6928 in 2017 to 8147 in 2019. Among those newly diagnosed in 2019 most patients had mild cognitive impairment or mild dementia (42% and 25% respectively). Weekly visits dropped by 60% following the suspension of face-to-face activity. However, by April 24th we were able to perform 78% of the visits we averaged in the weeks before confinement began and during that week 74% of programed appointments (475) already accepted telematic visit (350).

Discussion: We have shown that Fundació ACE model of care has been able to successfully adapt to a health and social critical situation as COVID-19 pandemic. We also expose pros and cons, detected on the implementation of this approach, for both, users and professionals to seize the opportunity to improve our model of care and experience. Overall, we were able to guarantee the continuity of care while preserving the safety of patients, families, and professionals.

SS3.2. Covid-19: Stress, anxiety and resilience in family carers caring for migrants with dementia

SMITS Carolien1, KOLSTE Roshnie1, WOLTERS Teuni2
1Pharos, Dutch Center of Expertise on Health Disparities, Utrecht, Netherlands, 2Pharos, Dutch Centre of Expertise on Health Disparities, Utrecht, Netherlands

Aim: Covid-19 measures have severely restricted personal contact between people with dementia and their relatives. Migrants with dementia and their relatives often need culture sensitive professional care. This prospective study aims for insights in the Covid-19 experiences of family caregivers of people with dementia from minority ethnic groups.

Method: Weekly semi-structured telephone interviews during three months with five family carers with a partner or parents receiving home or residential care throughout the Netherlands. Families have a Turkish, Moroccan and Moluccan cultural background. Topics include: experiences with Covid-19 measures, problems and solutions, support needs.

Preliminary results after 3 interview cycles: All family carers report anxiety and stress related to Covid-19 and the government measures. They miss personal contact with their loved one. Carers are concerned about the health of their family member and some observe increased loneliness, depression and cognitive decline. Care tasks require more planning and direction. Care tasks increasingly need to be done by a single caregiver, increasing carer burden. Carers appreciate care professionals, but are critical of care quality relating to: inconsistent use of protective measures, employment of flexible workers and time left for personal contact. Care may become less culturally sensitive as the older migrant has nobody to talk to in the native language. Furthermore, carers mostly obey government measurements. However, personal interpretations of the information may result in very strict hygiene measures. Muslims may be mentally and physically challenged by Ramadan routines. Most, but not all carers feel supported by relatives, neighbours and friends. Some need a relief of burden by professional care.

Conclusion: Covid-19 and government measures have resulted in anxiety and increased burden for migrant family carers. Professional care quality is under pressure and may become less culture sensitive. Further results will show changes over time as the Covid-19 pandemic and related measures develop.

SS3.3. In the midst of a global pandemic, what have we learned about remote care approaches using technology?

COOPER Nicola, FYFE Gillian
Alzheimer Scotland, Edinburgh, United Kingdom

Following lockdown in March, Alzheimer Scotland’s challenge was to find new ways to stay connected to service users, and crucially at this time, provide continuity of support.

In a few short weeks we had transformed our care approaches through the use of technology, experiencing a paradigm shift in how we deliver services.

Over 200 staff undertook digital skills training and now use the NHS approved Attend Anywhere video platform to deliver 1:1 support and a range of therapeutic group activities, including cafes and ceilidhs, for service users at home and in care settings.

There had been two critical factors making this possible: firstly, barriers experienced previously had been dissolved by the sudden, urgent need to support service users remotely; and secondly learning from our Scottish Government funded National Digital Projects had given us the knowledge base and evidence needed to take this forward rapidly, at scale.

Our aim was to understand how technology could be used to support PLWD to stay independent at home and to avoid preventable health and care admissions. We worked with 30 families, where one person had a diagnosis of dementia, to prescribe a personalised technology bundle supporting identified outcomes. Interestingly, even prior to the COVID19 outbreak, the greatest self-assessed need was to be able to stay connected and safe and we identified technology, including voice-based assistants, that fulfilled this function, enabling families to stay in touch and check in with loved ones remotely.
Our approach is closely aligned to National Strategic directives advancing Resilience within vulnerable populations and mitigating digital exclusion through the provision of equipment and mentoring in the “No-one left behind” initiative.

In responding to this national emergency, we have demonstrated that when utilised appropriately by an empowered workforce, technology can be an effective conduit of person-centred care, now and in the future.

**SS3.4. Emergency psychosocial supports during Covid-19 for people with dementia and their families**

ROCK Bernadette, O’PHILBIN Laura
The Alzheimer Society of Ireland, Dublin, Ireland

The outbreak of Covid-19 has forced the closure of almost all community-based dementia-specific services and supports in Ireland and abroad, leaving thousands of people with dementia and family carers to face this emergency alone. Innovative services are urgently required to meet the needs of people with dementia and family carers for the foreseeable future.

The aim of this research was to explore Covid-19 challenges, required supports, and desired solutions from the perspective of people with dementia and family carers. This represented a first step in developing a new suite of psychosocial supports and services for this cohort. Online and telephone surveys were carried out with 16 people with dementia, 95 family carers and 36 other stakeholders. Reported challenges included a) pervasive loneliness and social isolation, b) a lack of routine and boredom leading to a deterioration of symptoms of dementia and responsive behaviours and c) fear, anxiety, and feeling overwhelmed.

Most participants reported needing both practical and emotional support. Suggestions for interim support measures were mostly simple and inexpensive. These included regular ‘check in’ phone calls, peer support, more offline information, and engaging home-based activities. Some family carers also highlighted the need for respite. While offline (i.e. non-digital) support remains essential, there appears to be some desire for online interventions too (e.g. online activities and support groups).

Using this data, The Alzheimer Society of Ireland has developed a new suite of emergency supports and services for people with dementia and family carers. Drawing on qualitative and quantitative research, this presentation will provide an in-depth look at how Covid-19 is impacting people with dementia and family carers and the supports and resources that they require. We will also discuss our newly developed services and preliminary data on their impact and efficacy.

**SS4. It is time for European healthcare systems to prepare for Alzheimer’s breakthroughs**

GARNER Sarah1, SCERRI Charles2, SCHELTENS Philip3, SANTUCCIONE CHADHA Antonella4

1WHO, 2University of Malta, Malta, 3VU University Medical Center, Amsterdam, Netherlands, 4Biogen, Switzerland

For decades, the looming Alzheimer’s crisis has challenged policymakers and researchers alike. That may be about to change. A new wave of upcoming innovative disease modifying therapies (DMTs) holds the potential to change the course of the disease.

Currently, health systems in Europe are not ready to get the most out of these breakthroughs. To be able to fully benefit from these therapies, complex health systems will have to adapt and change. They will have to ensure that they can detect and diagnose dementia early, deliver new medicines by infusion, and monitor treatment.

While most of these improvements will need to be undertaken locally by national and regional governments, there are also significant steps that can be taken at European level to improve the life of patients affected by Alzheimer’s disease.

The panel discussions will give the opportunity to raise awareness about the need for European healthcare systems to plan for Alzheimer’s breakthroughs and identify solutions at national as well as European level to improve patients’ life. The time for action is now.

This session is organised by EFPIA.

**SS5. From brain health to Alzheimer’s disease – Addressing the challenges early in the patient journey**

GOODRICK Jayne1, WINBLAD Bengt2, SABBAGH Marwan3, DESTREBECQ Frédéric4

1Family carer, United Kingdom, 2Karolinska Institutet, Sweden, 3Cleveland Clinic, USA, 4European Brain Council, Belgium
Over the course of the last decade, research into the pathophysiology of Alzheimer’s has shown that early intervention will be important to maximize outcomes for the patient. Currently, detection, diagnosis and care planning all start once symptoms start to become more apparent, which is very often late in the disease course. To benefit from future advances in treatment and care, we need a healthcare system that appropriately recognizes, diagnoses and supports people with Alzheimer’s at the earliest stages of the disease – perhaps even before symptoms appear. Creating a policy response to drive the healthcare system to meet the emerging science will require support at both the Regional and Country levels to take urgent action.

In a time of social distancing and uncertainty in the world of healthcare, collaboration and communication among all stakeholders is more important now than ever. This year’s Alzheimer’s Europe Symposium will offer important perspectives from a variety of stakeholders in order to better understand the current state of treatment and care, and where we see challenges in the patient journey. Participants will examine ways in which healthcare systems are improving detection and diagnosis and review policy actions that can address barriers to challenges such as late stage or misdiagnosis.

The meeting will be moderated by Paola Barbarino, CEO of Alzheimer’s Disease International, and held virtually on October 22nd from 1 – 2pmCET.

This session is sponsored by Biogen.

**SS6. EAN: Medical management issues in dementia - the guideline of the European Academy of Neurology**

FREDERIKSEN Kristian Steen¹, VERDELHO Ana², KRAMBERGER Milica³, NILSSON Christer⁴

¹Danish Dementia Research Centre, Righospitalet, ²Department of Neurosciences and Mental Health, CHLNorte-Hospital de Santa Maria, University of Lisbon, ³Department of Neurology, Center for Cognitive Impairments, University Medical Center Ljubljana, ⁴Department of Neurology and Rehabilitation Medicine, Sk

Persons with dementia are at an increased risk of suffering from a number of comorbidities together with symptoms of dementia. Although no disease-modifying therapy exist for the neurodegenerative brain disorders causing dementia, adequate management of these issues may improve the quality of life and slow progression of the disease. However, a number of challenges such as lack of insight meaning that patients may not seek out medical assistance and lack of access to medical staff, may mean that patients with dementia do not receive proper treatment and management.

The present European Academy of Neurology Guideline addresses and gives guidance to physicians on a number of important medical management issues in the care of patients with dementia. This includes systematic medical follow-up, treatment of vascular risk factors, management of pain, treatment of agitation and aggression with anti-psychotic treatment and management of epilepsy in patients with dementia.

In the present session, four of the authors of the guideline will answer questions on issues related to the guideline after a brief introduction to the recommendations of the guideline.

This session is sponsored by EAN
Background: In the past decades, many efforts have been made in the development and evaluation of Assistive Technologies in dementia care. The progress in this field is promising but large-scale deployment of technologies in dementia care remains a challenge. Knowledge about implementation issues, may aid in preparing strategies for successful implementation of assistive technologies. The objective of this new initiative of the INTERDEM Taskforce Assistive technologies is to gain insight into factors related to successful and unsuccessful implementation of assistive technologies promoting social health for people with dementia.

Methods: An online survey was sent in Autumn 2019 to all INTERDEM members (n=206), researchers in the field of psychosocial dementia care in Europe and beyond. Members experienced with Assistive Technologies were invited to answer questions about (un)successful implementation of specific technologies. The survey addressed issues based on literature regarding implementation theories and frameworks, and practice. The results will be summarized and discussed in focus groups of relevant stakeholders.

Results: Forty researchers responded (19%) of whom 29 did not have experience with the topic. The other 21 researchers from Denmark, Czech Republic, France, Hongkong, the Netherlands and United Kingdom described in total 11 successfully and 9 unsuccessfully implemented technologies. Implementation issues were mentioned for different types of technologies, such as pill dispensers, an Alzheimer game, social robots and monitoring technology for safety.

The presentation will address implementation issues related to the properties of the device; characteristics of the users and context; policy, laws and regulations; implementation strategies; and outcomes of implementation of the Assistive Technologies.

Discussion: Successful implementation of Assistive technologies in different care settings can help provide adequate care and support for the growing number of people with dementia in the coming decades. Based on this study, recommendations for successful implementation of Assistive Technologies in dementia care will be provided.

P1.2. Best Practice Guidance Technology in Dementia – Recommendations from INDUCT Network Updated

INDUCT, the Interdisciplinary Network for Dementia Using Current Technology, is a Marie Sklodowska Curie funded Innovative Training Network, which developed a multi-disciplinary, intersectorial educational research framework for Europe with the aim to improve technology and care for people with dementia and to provide the evidence to show how technology can improve the lives of people with dementia. Within INDUCT (2016-2020) 15 Early Stage Researchers worked on projects in three areas: Technology to support every day life; technology to promote meaningful activities; and health care technology.

Transversal objectives of INDUCT were: 1) To determine the practical, cognitive and social factors needed to make technology more useable for people with dementia; 2) To evaluate the effectiveness of specific contemporary technology; and 3) To trace facilitators and barriers for implementation of technology in dementia care.

First recommendations resulting from the INDUCT projects were integrated in a web-based digital Best Practice Guidance on Human Interaction with Technology in Dementia (https://dementiainduct.eu/guidance/) which was launched in October 2019. Final recommendation of all
projects will be presented at the congress. These recommendations aim to support different target groups, i.e. people with dementia, formal and informal carers, policy makers, designers and researchers. By means of a selection tool each target group can easily find the for them relevant recommendations in the Best Practice Guidance. The main aim of the Best Practice Guidance is to improve the development, usage and implementation of technology for people with dementia in the three mentioned technology areas.

This Best Practice Guidance is the result of the intensive collaborative partnership of INDUCT with academic and non-academic partners as well as the involvement of representatives of the different target groups throughout the INDUCT project.

Acknowledgements: The research presented was carried out within the Marie Sklodowska Curie International Training Network (ITN) action, H2020-MSCA-ITN-2015, grant agreement number 676265.

P1.3. Playful multimodal activation with assessment of neuropsychological profiles in Alzheimer’s disease

PALETTA Lucas1, RUSSEGGER Silvia1, PSZEIDA Martin1, MURG Sandra1, ORGEL Thomas1, JOS Anna2, SCHUSTER Eva2, STEINER Josef2, DINI Amir1, KOSTER Ernst3, FELLNER Maria4

1JOANNEUM RESEARCH Forschungsgesellschaft mbH, Graz, Austria, 2Sozialverein Deutschlandsberg, Deutschlandsberg, Austria, 3Ghent University, Ghent, Belgium, 4digitAAL Life GmbH, Graz, Austria

A key problem in developing interventions in dementia care is the lack of knowledge about the mental processes and individual dependencies between functional impairments evolving over time. Neuropsychological profiles reflect the impact of the disease on distinctive neuroanatomic networks associated with complex cognitive domains. Recently serious games have been successfully validated with high potential as dementia biomarkers but increased estimation accuracy and personalised neuropsychological profiling is still required.

Tablet-PC-based intervention was applied within 10 weeks in Austria in terms of playful multimodal training and activation, engaging persons with dementia (PwD) with Alzheimer’s disease (AD) living at home (n=15, age M=81.7 years, MoCA score M=17.9). PwDs interacted with an integrated version of two serious games: 15 PwD played ‘MIRA’, a playful version of the anti-saccade task. 8 PwD played ‘MMA’, a suite of cognitive exercises (puzzle, memory, text gap filling). The games were introduced and assisted by trainers, some PwD learned to play alone.

The score of gaze-based MIRA showed significant correlation with MoCA score (Rho= .713**) and enabled individual MoCa score estimates with errors of less than M=2.6 MoCA points. MMA showed correlation with MoCA (Rho=p=.755*) and further MoCA subscores so that the neuropsychological profile could be established including impairments in visuospatial operations, attention, abstraction, language and recall.

The work outlined within the EU project PLAYTIME indicates successful steps towards daily use of gaze-based games. MIRA together with the MMA training enables continuous estimates of Alzheimer’s mental state in general but also to estimate individual neuropsychological profiles to identify personal impairments and their course over time. The playful training app was very well accepted by PwD users and offers with its pervasive mental assessment tool a large potential for future long-term monitoring in numerous AD care services.

P1.4. Evaluating a symptom tracking mobile app for use in people with dementia

DUNN Taylor1, STANLEY Justin1, STANOJEVIC Sanja1, ROCKWOOD Kenneth1-2

1DGI Clinical, Halifax, Canada, 2Dalhousie University, Halifax, Canada

Background: To address heterogeneity in dementia expression, numerous standardized tests are used for diagnosis and prognosis. SymptomGuide®-dementia offers an individualized approach to identify the factors that are most meaningful to patients. SymptomGuide®-dementia is a mobile app which allows caregivers to track only the symptoms of greatest importance to them. Here, we evaluated the feasibility of SymptomGuide®-dementia and described symptoms reported by caregivers.

Methods: SymptomGuide®-dementia is a freely accessible tool developed from qualitative analysis of Goal Attainment Scaling goals. To assess feasibility, we monitored the number of users, evaluated the completion rate and symptoms captured by the caregivers. Data were collected from launch in 2006 and exported on 2020-05-14. Users provided consent for data to be used for descriptive research.

Results: Of the 4724 SymptomGuide®-dementia profiles, 4193 were from the general public and 531 from the clinic settings. Patients were on average older adults (74±13 and 75±11 years), mostly women (62.9% and 55.1%), and with Alzheimer disease (49.7% and 59.0%), respectively. Clinic users were more likely to rate symptom change (54.3%) compared to the general public (13.2%). Users tracked a median of 4 symptoms (interquartile range 2-8), the most frequent being “Memory of Recent Events”, “Repetitive Questions/Stories”, and “Irritability/Frustration”. These symptoms were not often rated ‘most important’, however. The most important were generally related to aspects of everyday life, such as “Looking after Grandchildren”, “Travel”, and “Hobbies/Games”.

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Conclusions: SymptomGuide®-dementia offers a feasible approach to symptom tracking and a responsive approach to rating change in clinical settings. Individualizing care by allowing patients and caregivers the opportunity to help assess efficacy can be beneficial. It is essential to consider not only the size of the effect, but also whether that response is meaningful to patients.

P1.5. TeNDER - Co-creation of the intelligent support system with patients, carers and professionals

KRIVEC David1, HERNÁNDEZ-PEÑALOZA Gustavo2, GLIŠOVIĆ KRIVEC Špela1, FABJAN David1, GANGAS Pilar2, LOZANO HERNÁNDEZ Cristina María2, VRETOSS Nicholas3, DARAS Petros4, SCHÄPERS Barbara5, HINTERHOLZER Simone6, STEINBÖCK Martina3, MÜLLER Friedemann7, JAHN Klaus4, ÁLVAREZ GARCÍA Federico8, JIMENEZ RAMOS Jennifer9, CARRASCO MARIN Laura10, CIMINI Andrea11, RICCI Maria7

1Spominica - Alzheimer Slovenija, Ljubljana, Slovenia, 2Universidad Politécnica de Madrid, Madrid, Spain, 3Servicio Madrileño de Salud, Madrid, Spain, 4The Visual Computing Lab/CERTH-ITI, Thessaloniki, Greece, 5Schön Klinik Bad Aibling, Bad Aibling, Germany, 6Madrid Parkinson Association, Madrid, Spain, 7Department of Biomedicine and Prevention, University Tor Vergata, Rome, Italy

The Project TeNDER (affective basEd integrateD care for betteR Quality of Life) is developing an ICT based integrated care support system for patients with Dementia, Parkinson’s disease or cardiovascular diseases, their carers, social care and healthcare professionals. The project involves 13 partners: universities, health care organizations, patients’ associations, policy makers, industry and SMEs from 7 European countries, sharing the common aim to improve the quality of life of patients, carers and their care professionals. TeNDER takes into consideration existing services in Slovenia, Germany, Italy and Spain, where 5 large scale pilots are planned. The system is being co-created with end users, who are sharing their needs and wishes regarding the developed supporting technologies and services. Different "Personas", use cases and scenarios were designed with persons with different health conditions, together with people that surround them and taking into account the needs of care professionals. Use cases and scenarios are in the process of testing and validating.

During pilots, users will be involved in the process of iterative testing and validation of technologies (sensors, cameras that capture movement, affective recognition technology and basic health records) and higher-level services (active monitoring, warning and reporting, communication brokerage, virtual assistance and patient empowerment via data visualisation and personalised recommendations). Throughout TeNDER pilots usability and acceptance, together with the Quality of Life of users will be assessed and information about the services developed will be collected with surveys and interviews. With this approach, TeNDER creates the opportunity for patients, careers and professionals, to provide contribution through co-design process. Created services will alongside also foster opportunities for facilitating communication between social and health care professionals, and extending the autonomy of patients that would live more independently.

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No. 875325.

P2. Carers of people with dementia

P2.1. RHAPSODY, a web-based multimedia, information, and skill-building program for carers of people with young-onset dementia in the Netherlands

PEETOOM Kirsten1, DAEMEN Maud1, BAKKER Christian2, GROOT ZWAATINK Rob3, OOSTIJEN Andrea3, KOOPMANS Raymond3, VERHEY Frans1, DE VUGT Marjolein1

1Department of Psychiatry and Neuropsychology / Alzheimer Center Limburg, School for Mental Health and Neuroscience, Maastricht University, Maastricht, Netherlands, 2Radboud University Medical Centre, Radboud, Department of Primary and Community care, Nijmegen, Netherlands, 3Alzheimer Netherlands, Amerfoort, Netherlands

Young-onset dementia, with a symptom onset below age 65, has a profound impact on the person with dementia, and on the health and quality of life of family members as well. This is caused amongst others by behavioral changes, changes in family relationships, difficulties at work and financial problems.

The JPND funded RHAPSODY project aimed to gain insight in current policy and information provision regarding young-onset dementia in six European countries. Key results were a need for more information among carers on young-onset dementia and available care, but also a need for practical advice on how to cope with the caregiving situation and finances.

This resulted in the development and evaluation of a German, French, English and Portuguese version of a web-based multimedia, information, and skill-building program for carers of young-onset dementia. The program includes thematic modules that consist of written and video content, case-studies, presentations from professionals, and downloadable materials. A pilot study with 61 caregivers showed good acceptability and feasibility of the program.

Based on these positive results, the program is currently translated and adapted to the Dutch context, in close collaboration with Alzheimer Netherlands, the Dutch Young-onset Dementia Knowledge Center, experts, and end-users. This includes creating new video material with presentations from professionals, in which they among others explain the medical background of young-onset dementia and
reflect upon experiences from Dutch informal carers. Also written content on available care and support in the Netherlands is newly developed. The program will be incorporated on www.dementie.nl and evaluated by users in the summer of 2020.

**P2.2. Strategies to manage refusals of care: a comparison of family carer and care home staff experiences**

**BACKHOUSE Tamara**, **MIOSHI Eneida**, **JEON Yun-Hee**, **KILLETT Anne**

1University of East Anglia, Norwich, United Kingdom, 2University of Sydney, Sydney, Australia

**Background**: People in the later stages of dementia often need assistance with their personal care. Due to factors such as difficulties understanding, discomfort, or the caregiver approach, some people with dementia will refuse assistance with their care. Little is known about how family carers and care home staff cope with refusals of care on a daily basis.

**Aim**: To identify the strategies used for managing refusals of care in dementia in family and care home settings.

**Methods**: We conducted qualitative, face-to-face, semi-structured interviews with 20 family carers of community dwelling people with dementia and 12 care home staff who cared for people with dementia. Interviews were analysed using inductive qualitative content analysis.

**Findings**: The analysis generated four key themes: acting to prevent refusals occurring; communication strategies; leaving care undone or adapting care; support and safety. To prevent refusals family carers assessed the person’s mood before deciding to start a task, whereas care home staff were more likely to look for unmet needs or distract the person to get care completed. Both family carers and care home staff used encouragement and explanations to coax people with dementia through personal care interactions. Family carers reported showing their emotions, while care home staff simplified the sound of the task when talking to the person. Both groups would leave care undone or offer reduced care when faced with determined refusals. Family carers had far less support to manage refusals than care home staff who drew heavily on the staff team around them.

**Conclusion**: Our findings demonstrate the different experiences and skills of family and care-home caregivers when coping with refusals of care. Learning from each context can enable us to gain a comprehensive overview of strategies in use, some of which could be transferred to the other setting to aid better management.

**P2.3. Portrait of Carers and Dementia perceptions in France: evidence from Elders 4 (survey on longevity, dependency, risk and support)**

**ZERRAR Nina**

Mederic Alzheimer Foundation, Paris, France

Who are the carers? What are their difficulties? How do they define dementia? Do non-carers perceptions differ from carers’ ones? All these questions drove Mederic Alzheimer Foundation’s new survey: Elders 4. Elders 4 inherits from 3 waves of analysis of dependency risk perceptions and informal care provision. This fourth wave aims at focusing on dementia perceptions; this focus will result in a barometer describing dementia perceptions and how these perceptions vary with having and helping relatives with dementia.

At the time this abstract is being written, the survey is still in the field, but we can already give some information. The Elders 4 protocol relies on two questionnaires: one for the main respondent and the other for his or her partner when he/she has one. This protocol allows us to enter households and gain a better understanding of how households organise themselves to face relatives’ care needs; in particular, relatives with dementia.

10 000 households were selected to receive Elders4’s questionnaires and ensure the representativeness of the final sample to the French population aged between 40 and 79 years old. We expect around 7 500 households to answer but the return rate might be lowered due to the covid-19 crisis. Nevertheless, we have already received 6 500 households’ answers. As an illustration, the following items will be part of our analysis (translated from French):

- If you reach age 80, how likely are you to live with dementia?
- In your opinion, are you enough informed about dementia?
- Since you learned that your relative has dementia, how has your relationship with him/her evolved?

These questions will be analysed with regards to the household’s informal care provision and dementia ‘experience’.

The presentation will produce an overview of the most salient facts highlighted in this very unique dataset.

**P2.4. Comparing carer burden in family carers of people with and without dementia: An Irish national dataset**

**TEAHAN Áine**, **LAFFERTY Attracta**, **CULLINAN John**, **O’SHEA Eamon**

1Centre for Economic and Social Research on Dementia, NUI Galway, Galway, Ireland, 2CAREWELL Project, University College Dublin, Dublin, Ireland, 3School of Business and Economics, NUI Galway, Galway, Ireland
Background: Despite the policy relevance of carer burden, limited research focuses on family carers’ experience of carer burden among different disease groups, especially among those caring for people with and without dementia. This study aimed to examine differences in carer burden in a sample of family carers providing care for people with and without dementia.

Methods: Secondary data analysis was conducted on an Irish national cross-sectional dataset of 2,311 family carers of older people receiving a government funded Carer’s Allowance. Multivariable ordered logistic regression was used to analyse four levels of carer burden (low; mild; moderate; high). The main independent variable of interest was diagnosis of dementia, while controls included a range of variables relating to the person being cared for, the family carer, and the context of care.

Results: One-fifth of survey respondents cared for a person with dementia. Our analysis identified a range of variables that were significantly associated with carer burden. These variables included dementia diagnosis, dependency level, education, residence, co-residence and perceived support. Compared with family carers of people without dementia, family carers of people with dementia were significantly less likely to report low or mild carer burden (-6.95 ppts and -3.64 ppts respectively) and significantly more likely to report moderate or high carer burden (8.46 ppts and 2.13 ppts respectively).

Conclusion: To conclude, family carers of people with dementia are likely to experience higher levels of burden than those caring for people without dementia. Caring is not a homogenous task, so policy makers and support systems need to respond in different ways to different caring situations. In addition, while previous research points to dementia symptomology as the main contributor to carer burden, our findings suggest that wider social factors also play a significant role.

P2.5. A qualitative study of the everyday life and well-being among young relatives of parents with dementia

NIELSEN Marianne Lyngmose, BJØRNSKOV Stina, GREGERSEN Rikke
VIA University College, Aarhus, Denmark

Background: In Denmark, approximately 3000 persons aged 30 or below have a parent with dementia. So far, efforts to support young people with parents with dementia have been sparse and up until recently, they have constituted an overlooked group in the Danish welfare system.

Previous research has shown that adult relatives are severely affected regarding both their everyday life and well-being. Experiences from practice and preliminary research suggest that young relatives may face similar challenges. However, knowledge on these topics is inadequate.

Aim: To explore how 18-30 year-olds experience their everyday life with a parent with dementia and how the life situation affects the youngster’s engagement in leisure activities, social life, education and work. The long-term goal is to contribute to improve preventative efforts and support provided by professional caregivers to this marginalized group.

Methods: In May to August 2018, a qualitative interview study among relatives aged 18 to 30 years was performed (7 Females, 4 Males). Participants were recruited through dementia associations, social media and professional caregivers. Qualitative data were obtained by 11 semi-structured interviews using a themed interview guide. Data were analyzed and interpreted in a phenomenological-hermeneutic perspective.

Results: The situation of the young relatives was described by three main themes: Concerns, Change of roles and Responsibility/Chores. The young relative’s conditions within the three themes had direct consequences for their daily lives in relation to, for example, their education, work, social life and opportunities to take care of themselves. Activities usually related to adolescence and early adulthood were often downgraded due to their parents’ dementia.

Conclusion: The everyday lives of the young relatives regarding education, work, social relationships etc. were heavily affected by the circumstances that accompany their parents’ dementia diagnosis.

P3. Efficient data sharing: a must for science to respond to societal needs

P3.1. Harmonisation of health data as a critical enabler for rapid actionable evidence for neurodegenerative diseases

HUGHES Nigel
Janssen

As for all diseases, health data is siloed, in different systems, schemas, vocabularies and ontologies, let alone languages, both human and machine. Aside from clinical trial data, clinical or real world data is not collected for the primary purpose of research, and as such is messy, with varying quality. Rapid answers to an exponential rise in areas of inquiry, especially for chronic diseases with limited treatment options is a challenge of our age.

Exemplars of approaches to remedy this in neurodegenerative diseases over the years have included IMI EMIF-AD, GAAIN, IMI ROADMAP, MS Data Alliance among others. In this presentation the opportunity and challenges will be explored to accelerate research in this domain via data harmonisation at scale and across federated networks and the like.
Harmonising data via common data models and utilising standardised analytical tools is growing rapidly as an approach to the research challenge per se, and projects and programmes that incorporate this are expanding. Being able to keep data local, with distributed querying, reduces the socio-technical challenges for data custodians, from hosting and security, to GDPR compliance and consent, whilst being able to transgress geographical borders to a global scale. Furthermore, such approaches incorporate ‘network effects’ of facilitating open science collaborations for all key stakeholders with a common research agenda. Nevertheless, technical, methodological and semantic/syntactic problems, as well as persuading stakeholders to collaborate need to be explored and responded to.

As such, and with the significant challenge of finding optimal therapeutics and ultimately cures for many neurogenerative diseases remaining elusive, data harmonisation, networks and open science collaborations will likely be crucial in amassing the critical mass of data, researchers and Industry to respond to the needs of patients in the nearer time.

P3.2. Enabling analysis of pan-European datasets: the EPAD analytical database

BARNES Rodrigo
Aridhia Informatics

The development of clinical and scientific solutions can be hampered by patchy and evolving data, as well as the difficulties of distributing analytics-based tools to where they are needed. To address this important issue, Aridhia has developed a Digital Research Environment (DRE) service for securely sharing patient and participant data and running state-of-the-art statistics and machine learning in the cloud. The DRE has been designed to make data sharing convenient and secure for communities like EPAD and their wider ecosystem. In this presentation, we will discuss how platforms such as the DRE can improve the potential for data discovery and reproducibility in science, and deliver decision support tools to the clinic at scale.

P3.3. Data discovery to support data sharing to support data analysis

VEAL Colin
University of Leicester, United Kingdom

Data discovery, sharing (or more precisely access) and analysis are fundamentally different activities. However, they do have inter-relationships which can be represented as three corners of a triangle. Each and every data processing activity sits somewhere within the area of that triangle. Different rules, requirements, consents, use conditions, laws, expectations and challenges apply to each of these corners of activity. It is a mistake to try to develop monolithic support systems for all three of these topics, as this leads to uncertainties, contradictions and slow progress. Instead, a better approach is to create specialised technical solutions for each corner of the triangle, and then bring these together. An example will be presented that tackles the discovery corner, in the context of federated discovery of core data and subjects suitable for inclusion in a longitudinal preclinical and prodromal AD cohort (as established by the IMI EPAD projects).

P3.4. Adopting best practice on data sharing: report on Neuronet Working Group activities

RINALDI Manuela1, STEUKERS Lennert2
1Janssen Pharmaceutica NV, On behalf of MODIS Life Sciences, Belgium, 2Janssen Pharmaceutica NV, Belgium

There is a wealth of scientific data buried in the archives of hospitals, academic institutions, private sector, and other stakeholders that has not yet been leveraged to its maximum. The sharing of data useful for research and clinical practice is increasingly viewed as a moral duty, especially in the neurodegeneration field where major breakthroughs and interventions being brought to market are still pending. However, despite the willingness and general ethos of data sharing to advance the field, in practice, it still proves to be quite challenging due to various technical, ethical, legal, financial, cultural and even psychological issues that typically hamper data sharing. Another challenge is the variability (lack of standardization) in how data are being collected and the format of these datasets (lack of harmonization).

Within and between various Innovative Medicines Initiative Joint Undertaking (IMI JU) projects (beyond neurodegeneration), similar challenges have been identified and hamper project progress. Various IMI consortia have been created to address parts of the global challenge of data identification, standardization, harmonization and eventually large-scale community use.

Neuronet is an IMI2 Coordination and Support Action (CSA), aiming to support and better integrate projects in the growing IMI Neurodegenerative Disorders (ND) portfolio. This presentation gives an overview of the main topics that will be addressed in the Neuronet “Data sharing and re-use” Working group (WG). The main aim of this Neuronet WG is to develop specific guidance to aid projects on data sharing policies and tools, incentives, value propositions, infrastructural solutions, etc. The obtained results will not only be of high value to the IMI Neurodegeneration portfolio, but also to any other initiatives that have the ambition of or rely on establishing Big Data-driven research platforms.

This session is organised by Neuronet.
P4. Interactive INTERDEM academy seminar: ethical dilemma's in research practice

HORSTKÖTTER Dorothee¹, VERHEY Frans¹, DASSEN Fania²

¹Alzheimer Centrum Limburg, Maastricht, Netherlands, ²Maastricht University, Maastricht, Netherlands

We are all fully aware of professional ethics, aren’t we? It turns out that things sometimes can be more complex than we perceive, and a continuous awareness in situations where ethical issues are involved is required. Ethics are an important part of our daily research practice, and discussing ethics-related themes will become part of our DNA if we try to question our own ethics and beliefs regularly.

We hope that you agree with us on this. During this INTERDEM Academy seminar, we will focus on ethics in daily research practice. We will start the session with a case example. Next, an introduction will be provided by ethics expert Dorothee Horstkötter from Maastricht University. This introduction will be followed by an interactive discussion of the case example, in which you will all be invited to actively provide input. At the end there will be plenty of time for Q&A on the topic and to bring in and discuss your own examples with our ethics expert.

After the seminar, you will receive an invitation to participate in a follow-up INTERDEM Academy session (to be organized). In this session we will play the ‘Dilemma Game’, a game which can help us to address integrity issues during our careers as a scientist.

This seminar is organized for members of the INTERDEM Academy; interested researchers who are not part of this network are also welcomed. The INTERDEM Academy has been established in 2014, and it has been committed to stimulating the career development and capacity building of researchers in the area of psychosocial interventions and timely diagnosis in people with dementia, and has grown to around 200 early stage researchers. For questions, please contact the executive office (interdem-masterclass@maastrichtuniversity.nl).

P5. Post-diagnostic support

P5.1. How can Meeting Centres support people affected by dementia to adjust to change during a period of physical distancing?

EVANS Shirley, BROOKER Dawn

Association for Dementia Studies, Worcester, United Kingdom

A Meeting Centre (MC) is a local resource, operating out of ordinary community buildings, that offers ongoing warm and friendly expert support to people and families affected by dementia. A key aspect is regular face to face contact with other people. MCs, as part of the UK Meeting Centre Support Programme (UK MCSP) established and led by the Association for Dementia Studies, University of Worcester, rapidly needed to find innovative ways to support those isolated at home during the pandemic.

Approaches included activity packs, telephone calls, handwritten letters, weekly newsletters and the use of technology such as Zoom and WhatsApp for seated exercise, poetry reading, singing and group and individual contact and carer meetings.

As part of the UK MCSP, MCs are required to collect data which usually covers attendance data; baseline data for new members; satisfaction questionnaires every six months; referrer feedback; contextual statements and case studies and health and well-being at the start then every six months. During the COVID-19 period this data was adapted to increase the health and well-being questionnaires to every three months and extended to include semi-structured interviews and focus groups with stakeholders to develop an understanding around what people affected by dementia were experiencing as the pandemic progressed.

Perspectives from all stakeholders were analysed to inform strategies to support people to adjust to their changing situation due to a diagnosis of dementia during a period of global instability. Results of the study will be presented together with an outline of a set of guidelines as to how community-based interventions such as MCs can continue to support people with dementia at a distance.


P5.2. Planning dementia-capable community-based housing for adults with intellectual disability

JANICKI Matthew

University of Illinois at Chicago, Rockport, Maine, United States

The WHO notes that adults with intellectual disability (ID) are a high-needs population among persons with dementia (this includes adults with Down syndrome [DS] – a noted risk factor for Alzheimer’s disease). Provider organizations are challenged by increasing numbers of adults with ID needing specialty dementia care in community settings. Questions arise as to what to consider when planning structural
and functional specialty dementia-care housing for persons with ID. A longitudinal study, begun in 2011, is following 3 group homes (N/each=5) providing specialty dementia-care to 15 adults with ID and provides insights for planning specialty housing care. Data show a pattern for admission ages (3 age-of-admission clusters - \(\chi^2=50.5; \chi^2=57.1; \chi^2=66.8\)); length of stay (\(\chi^2=4.12\) yrs); mortality (\(\chi^2\)-age-death=65.4; \(\chi^2\)=69.3; DS=56.3); age at entry (\(\chi^2=59.1\) years from entry to death (\(\chi^2=5.4\) yrs); and multimorbidities (high number generally, but decreases among survivors). Staffing higher for homes with residents with advanced dementia. Home layouts are single floor with private and public spaces. Findings noted that adults with DS required earlier admissions but had more life-years in the GHs than older adults admitted at later age but who succumbed earlier to disease complications. Small group homes (GHs) are a viable option for in-community long term dementia care. General planning for dementia GHs should consider home lay-outs (aiding mobility, gathering, being barrier-free) and dementia care aids (bathing, quiet spacing, dining, exercising, etc.); transitions associated with varied trajectories of decline, earlier mortality linked to complexity of pre-existing conditions and progression of dementia; and changes in the focus of care needs over time (including advanced dementia and end-of-life care). Clinical planning should factor in age at entry, dementia-stage, type of dementia, mortality expectations and end-of-life care, status, patterns of care needs, dementia-related behaviors, aging-related issues, and probable trajectories of decline of the residents.

P5.3. Exploring models of post diagnostic support in England

WHEATLEY Alison, BRUNSKILL Greta, BAMFORD Claire, ROBINSON Louise

Newcastle University, Newcastle upon Tyne, United Kingdom

The overall aim of the PriDem project is to develop and test new ways of providing post diagnostic support for people with dementia, with a focus on support led by primary care. We used qualitative methods to explore current models of post diagnostic support to find out which aspects work well and identify where changes are needed. We then selected six services from our initial work to explore in depth. This involved observation of service delivery as well as interviews and focus groups with health and social care professionals, people with dementia, and informal carers.

In this presentation, we compare three contrasting models of post-diagnostic support: a comprehensive secondary care-led model; a comprehensive Admiral Nurse-led model based in a GP practice; and a GP-led model covering multiple practices. The models varied along a number of axes, including where, when, how often, and by whom services were provided. The exact nature of the post-diagnostic support provided also varied; while each of the services offered regular review and follow up for people with dementia, other features such as access to rapid advice from specialist mental health services or shared access to primary care notes were not available in every service. Services also varied according to how well they were embedded within the local dementia care pathway. We draw on our data from people with dementia and their families to evaluate some of the benefits and challenges of each approach for service users, as well as data from staff in linked local services to explore the benefits and challenges from a professional perspective.

Data collected as part of this project are currently being used as part of a co-design process to inform the development of a new intervention to provide post-diagnostic support for people with dementia.

P5.4. Needs of people with dementia and their caregivers: Development of the Erlangen Needs Assessment in Dementia (ENA-D)

DIETZEL Nikolas1, KÜRTEN Lara1, MEUER Sebastian1, ICKLER Dorothee1, GRAESSEL Elmar2, KOLOMINSKY-RABAS Peter1

1Interdisciplinary Center for Health Technology Assessment (HTA) and Public Health (JZPH), Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany. 
2Center for Health Services Research in Medicine, Department of Psychiatry and Psychotherapy, University Hospital Erlangen, Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany

Background: 70% of the people with dementia (pwd) in Germany live in their home environment, cared by close relatives. In order to prevent caring relatives from becoming the invisible second patient, it is highly important to identify their needs. As existing instruments for needs assessment are extensive, complex, or not target-group-specific, we aimed to develop a compact needs assessment instrument as part of the research project ‘Digital Dementia Registry Bavaria (digiDEM Bayern)’. 

Method: In a first step we conducted a focus group including professionals and caregivers as experts. Main objective was the identification of support services as foundation for the need’s expressions in the instrument. In a second step, the experts should evaluate the identified services according to the relevance for dementia care. The highest rated services (scale from 1 (not important) to 10 (important)) will be included in the instrument.

Results: 13 professionals and 4 caregivers participated in the focus group. In total, 72 different support services could be identified. Conclusion: Caregivers experience multiple factors causing a high caregiver burden and are therefore reliant on support. The ENA-D facilitates caregivers to directly express their individual need of specific support services. Thereby, the ENA-D is easy to understand and of a small length, so that conduction is not overstraining. Using the ENA-D, supply gaps can be identified and transformed into a specific regional
health care planning. Thus, the ENA-D is an important and compact needs assessment instrument that can be included in both scientific and consultation contexts. Funding: digiDEM Bayern is funded by the Bavarian Ministry of Health and Care as part of BAYERN DIGITAL II (funding code: G42d-G8300-2017/1606-83).

P5.5. Withdrawn

P6. Minority ethnic groups

P6.1. What are barriers and facilitators to provide culture-sensitive care?

CLAEYS Ann1, CLAEYS Ann2, BERDAI-CHAOUNI Saloua2, TRICAS-SAURAS Sandra3, DE DONDER Liesbeth4

1Erasmushogeschool, Brussels, Belgium, 2EHB, VUB, Brussels, Belgium, 3ULB, EHB, Brussels, Belgium, 4VUB, Brussels, Belgium

Background: Research suggest that culturally-sensitive care is essential to meet the needs of persons with a diagnosis of dementia (PwD) and with a migration background in order to provide excellent care. Scientific evidence also shows that healthcare (HC) providers struggle with the implementation of culturally sensitive care. Yet, it is unclear though why this approach to care is so difficult to implement in practice. Therefore, the aim of this research is to identify the potential barriers but also the facilitators that HC providers experience when delivering care to PwD with a migration background.

Methods: A total 6 focus groups (n = 37) and 12 in-depth interviews were conducted with HC providers (i.e. doctors, nurses, social workers, occupational therapists, nursing and medical students). Thematic content analysis was used to analyse the data.

Results: First, the results show that HC providers narrate about people with a migration background and their families as “the other”. This “othering” runs like a thread through the barriers that HC providers experience in providing culturally sensitive care. Respondents narrate about the person with a migration background as someone with limited health skills, with a language barrier, with financially limited resources and who refuses care. Second, this anticipated problematization of older migrants with dementia renders the HC providers feeling incompetent and insecure to provide care to these perceived ‘others’. Third, organizational aspects at the exo level, such as time pressure or economic restrictions, are also perceived as a barrier by HC providers in the provision of culturally-sensitive care.

Conclusion: HC providers experience barriers in the provision of culturally sensitive care to PwD with a migration background. Eliminating these barriers should mainly have to focus on conceptualisation, because “othering” appears to be an important cause of various barriers. This study is part of the Diverse Elderly Care project on culturally sensitive dementia care in Brussels.


FRANZEN Sanne1, VAN DEN BERG Esther1, PAPMA Janne1, NIELSEN Rune2

1Erasmus University Medical Center, Rotterdam, Netherlands, 2Danish Dementia Research Center, Copenhagen, Denmark

Objective: The increasing diversity in the European Union (EU) calls for adaptations to neuropsychological assessment practices. The aims of this study were to examine the current state of cross-cultural neuropsychological assessment in the EU and to provide recommendations for researchers and policy makers on this topic.

Methods: Twelve experts from nine EU countries participated in a Delphi consensus study involving two sequential rounds of web-based questionnaires and an in-person consensus meeting. The experts individually rated on the basis of importance (scale 1-10). The degree of consensus was determined by assessing quartiles and medians.

Results: Across the EU, several cross-cultural (adaptations of) neuropsychological tests are available, as well as a limited number of initiatives for the training of professionals. The main priorities that were identified were the development of tests (median importance rating 10, Q1-Q3: 9-10) and norms (median importance rating 9, Q1-Q3: 8-10), as well as training, awareness, and knowledge regarding cross-cultural assessment among European neuropsychologists (median importance rating 9, Q1-Q3: 8-10). The focus should be on tests of social cognition (median 9, Q1-Q3: 8-10) and language (median 9, Q1-Q3: 7-10), closely followed by other domains, particularly executive functioning (median 8, Q1-Q3: 8-10). A list of recommendations was generated describing essential skills and knowledge necessary for cross-cultural neuropsychological assessment. Conclusions: The development and availability of cross-cultural tests and norms should be prioritized, as well as the development and implementation of training initiatives across the EU. Furthermore, EU guidelines could be established for working with interpreters in a neuropsychological assessment.

P6.3. Comparing national dementia plans and strategies in Europe – Is there a focus of care for people with dementia from a migration background?

SCHMACHTENBERG Tim1, MONSEES Jessica1, HOFFMANN Wolfgang1, VAN DEN BERG Neeltje2, STENTZEL Ulrike2, THYRIAN René1

1University of Bremen, Germany, 2University Medical Center Hamburg-Eppendorf, Germany
Background: People with migration background (PwM) and dementia are a vulnerable group. Providing care for this group is a public health challenge in Europe. An increasing number of countries are issuing national dementia plans (NDPs), but a systematic overview of NDPs of European countries focusing on care for PwM is lacking. This study aims to illustrate how European countries identify the dementia-related needs of PwM and whether there are specific healthcare services for them at the national level.

Methods: A qualitative analysis of NDPs of the EU and EFTA countries was carried out. Using the discourse analysis model according to Keller (2011), documents were systematically screened for their relation to migration via keyword and context analysis. The content of the migration-related sections was analyzed using the methods of paraphrasing, memos, comments, and open coding.

Results: Twenty-three of the 35 EU and EFTA countries have a national dementia plan, ten of them refer to migration and one country (Austria) has a national dementia plan with a chapter on migration. Eight NDPs identify that PwM and dementia have special needs, and actions to care for this group are planned in nine countries. However, only Norway, Northern Ireland, and the Netherlands refer to available healthcare services for PwM. Overall, the topic of migration plays a subordinate role in the NDPs of European countries.

Conclusions: The current lack of migrant-specific healthcare services in almost all European countries may lead to denying the right to appropriate care to a growing population. The topic of migration must be given greater attention in NDPs. European countries should develop strategies with specific services that address the needs of PwM. To improve comparability at the European level, a common definition of migration is needed.

P6.4. Providing suitable care to older migrants with dementia in Belgium: perspective of family caregivers on accessibility and acceptability of professional dementia care.

BERDAI CHAOUNI Saloua1-2, CLAEYS Ann1-2, DE DONDER Liesbeth2
1Erasmus University College, Brussels, Belgium, 2Vrije Universiteit Brussel, Brussels, Belgium

Workers from Italy, Morocco and Turkey travelled towards Belgium within the context of labour migration during the ’50 and ’60 and are now ageing in cities and regions hosting these labour migrants such as Brussels. At present, Moroccan, Turkish and Italian older persons are large groups of 65+ with a migration background living in Brussels. An increasing group among this older population is facing dementia. Family and professional caregivers are challenged to provide suitable care to these older migrants. This study explores the service use by family caregivers of older labour migrants. Which services do they use? What are the underlying reasons to use, keep using or not to use these services? Thirty four family caregivers with Italian, Moroccan and Turkish origin are interviewed about their experience with professional dementia care. Results indicate that although aging at place is preferred by the family caregivers, use of different dementia care services is inevitable and starts during the diagnostic phase. Family caregivers experience a poor accessibility of the professional dementia care which enhances their care burden. Reasons not to use professional care are the lack of person-centered care and the insensitivity of professional care to the care-recipients’ ethnic, religious and social background. Family caregivers encounter different barriers in their search for suitable care for their older family members with dementia. The current used care solutions are based on their perseverance and creativity. A supporting professional dementia care, that is sensitive to the intersection of the identities of these older persons and their family caregivers, is required.

P6.5. Cultural-sensitive memory work in Finland: The Memory Interpreter training program

JAASKON Siiri
Society for Memory Disorders Expertise in Finland/ ETNIMU-activity, Helsinki, Finland

Aim: The aim of ETNIMU activities is to secure that people from ethnic minority backgrounds with dementia get timely and accurate diagnosis.

Background: The MMSE is the memory test most commonly used with people from ethnic minority backgrounds in Finland. The test is well suited to the native populations, but it falls short when used to map the situations of people from diverse ethnic minority backgrounds. To get the necessary information, the test needs to screen also for background information f.ex. about a person's daily life, skills and social activities. Difficulties in language and insufficient understanding of the cultural specificities pose the biggest challenges to mapping. The social and health care professionals would benefit of an interpreter who can help them perceive the client's possible memory problems and provide them assistance in memory test situations.

Method: The pilot group of the Memory Interpreter training program has 17 participants of Estonian, Russian, Arabic, Chinese and Roma backgrounds. All participants are volunteers. The training program consists of a theory part that covers f.ex. general information about dementia, interpreting skills, confidentiality and GDPR. The training is completed by a practical session at a Memory Clinic. After completing the training, the memory interpreters act independently as interpreters in memory test situations and help the social and health care professional in their interactions with clients from different ethnic minority backgrounds.
Results: ETNIMU activities have developed a unique training program in Finland that supports culturally sensitive memory work in co-operation with memory clinics, universities, as well as experts working in various fields. The Memory Interpreter training program and the working tools can be adapted to work with different language and cultural backgrounds and so help to secure timely and accurate diagnosis of dementia.

P7. Ensuring ethics and patient privacy whilst boosting research

P7.1. Two Peas in a Pod: ethics and data protection for neurodegeneration research

NATHAN Lea
Nathan Lea MBCS

The distinctions that exist between Ethics and Data Protection regulations should not cause a divergence in how researchers and participants understand and apply them in practice. This talk will highlight the relationships that exist between the two and why they are symbiotic for delivering assured research that is transparent and helps to enhance the understanding of neurodegenerative conditions.

P7.2. Preservation of autonomy throughout dementia

CAÑABATE Pilar, BOADA Mercè, PRECKLER Silvia, MORENO Mariola, ROSENDE Maitee, MAULEÓN Ana, HERNÁNDEZ Isabel, MARQUÍ Marta
FUNDACIO ACE, Spain

The current pattern of care for people with dementia is reactive and paternalistic. Reactive because scenarios are rarely anticipated to design strategies and actions. Paternalistic, since in the management of the disease the principle of autonomy is hardly preserved. A moral question immediately arises: How to ensure that decisions are "in favor of the person" and not "in his place"? or how to ensure that the principle of autonomy ("what X would have wanted") is not replaced by the principle of beneficence ("what is best for X")?

Compassionate harassment in caring for people with dementia is frequent. The ethical interpretation of this procedure can be ambivalent. There is no maleficence in the sense that there is no negligence, but excessive care, which appropriating the will and capacity of the person, affecting their autonomy, can be considered as maleficence.

A diagnosis of Mild Cognitive Impairment opens up the opportunity to plan guidelines to avoid such peril. But the accumulated experience from MOPEAD shows that the existing instruments consist in planning the hypothetical situation of a terminal illness or the unlikely situation of a coma. But those scenarios have nothing to do with the practical decisions that should be made if they develop dementia.

Objective: Pinpoint the different scenarios and make an inventory, which will be taken during the disease, to go from a paternalistic model to an autonomist model, while the values that govern their care will be their own.

Method: Caregiver-family discussion groups, in-depth interviews and participant observation in the ACE Foundation. The informants' narratives were recorded, transcribed and analyzed. A preliminary decision guide was developed and reviewed by the participants.

Results: Six areas of foreseeable situations are distinguished: care; image; risks and restrictions; health and research, intimate relationships and end of life.

This session is organised by Neuronet.

P7.3. Remote monitoring and digital devices: ethical and patient privacy implications in the RADAR-AD project

LIBERT Sébastien ¹, LUCIVERO Federica ²
¹University College London, London, United Kingdom, ²University of Oxford, United Kingdom

In line with important developments in digital technologies and their recent spread in society, remote monitoring technologies (RMTs) embody a promising domain of research for dementia while bringing novel ethical challenges. This presentation covers ethical issues relating to the new role of participants, their expectations, and the question of privacy in this type of research. It reports findings from the ethics component of the RADAR-AD project studying the relevance of RMTs for assessing cognitive decline in dementia. This ethics component was based on prospective interviews with 6 people with dementia/Mild Cognitive Impairment and 5 caregivers/supporters part of the Patient Advisory Board (PAB) for the project. These interviews questioned their perspective on ethical challenges in this type of research based on their experience of dementia or caregiving/providing support. This presentation will discuss ethical challenges mentioned in these interviews. They concern:

• The new roles and responsibilities of participants in RM research when monitoring their daily life.
• The expectations of participants in this type of research, notably regarding feedback about the data collected and dementia progression.
• The multiple meanings that participants attribute to privacy.
Correspondingly, to address these challenges, this presentation will discuss ways to:
• Actively engage participants in the research and address eventual participants’ anxiety linked to feeling responsible for the research outcomes.
• Respond to requests of feedback sensibly while signposting obstacles relating to the sensitivity and uncertainty of information relating to dementia progression.
• Address these multiple expectations of privacy in the consent process.
Overall, this presentation hopes to help address ethical concerns in dementia research drawing upon the potential of RMTs for the benefit of researchers and participants.

**P7.4. Adopting best practice on patient privacy – report on Neuronet Working Group activities**

BRADSHAW Angela
Alzheimer Europe, Luxembourg

Compliance with the ethical and data protection requirements that underly patient privacy is seen as pivotal to achieve real excellence in health research. However, patient privacy can sometimes be viewed as a barrier to health research, in particular research that involves secondary use (or re-use) of clinical data. Neuronet aims to help IMI neurodegeneration projects navigate the ethical and data protection challenges that inevitably arise in health research projects that involve human participants. In 2019, Neuronet created a Working Group (WG) on Patient Privacy and Ethics to compile and share learnings on this topic, thereby ensuring best practice, limiting duplication of effort and developing resources that will be of value to existing and future IMI projects. This presentation will report on the activities of the Neuronet WG on Patient Privacy and Ethics, including the development of guidance on standards and practices for protecting patient privacy and a preliminary exercise to map the ELSI activities of IMI neurodegeneration projects in the Neuronet programme.

This session is organised by Neuronet.

**P8. INTERDEM: Covid-19 and its challenges to social life in various European settings and phases of life**

The focus of INTERDEM on social health provided knowledge that became actual and valuable in understanding the impact of the Covid-19 pandemic. The key measure to combat Covid-19 is social distancing. This deprives older adults from direct interaction with their social environment and thereby undermines the potential of social health to preserve their quality of life. Social health reflects the competencies of the individual to participate in social interaction and the influence of the social environment on the individual’s balance of capacities and limitation. The disturbance of this balance by social distancing became painfully evident in recent studies on the consequences of quarantine and social isolation.

In this symposium we describe the challenges to social life within the European societal context. Protective measures made populations home bound for months, focused on the risk of social contacts and warn for new outbursts. We describe the influence of social distancing on social, mental, cognitive and physical functioning and raise the question on how to balance between protection and its risks. Social life differs according to its environmental context. Community life during the pandemic is restricted and these restrictions differ according to their setting. We will provide a picture of the Polish general population under quarantine and its age related consequences. For people with dementia and their families, the supportive facilities have been blocked. We provide a picture of those who used to join the activities organized by Italian meeting centres and Alzheimer cafes. Long term care facilities have been hit extremely hard, not only by the virus, but also by isolation measures. The Dutch situation in the phase between lockdown and opening will be described. Our information on these issues will facilitate the discussion on care and social isolation. We are happy to exchange thoughts with you.

**P8.1. Social distancing: protection and risk**

VERNOOIJ-DASSEN Myrra
Radboud University Medical Center, Nijmegen, the Netherlands

Social distancing started as a strategy to combat the acute threat of the Covid-19 virus, but turned gradually into a long-term measure. The sprint became a marathon. This requires adaptations in order to reduce the risks of the protective measures that disturb our social life. What is the impact of social distancing and which management strategies can be used to reduce harm? A flow of scientific literature provided rapid knowledge on the impact of the pandemic. The impact is immense. The social distancing had a negative impact on social, mental, cognitive and immune
functioning. The results also demonstrate the adaptive capacities of people by use of technology and neighbourhood resources. It is too early for intervention results, but useful strategies have been suggested to reduce the damage of social distancing.

Recent research provided evidence on the immense influence of social connections on cognitive and mental functioning. This supports the hypothesis that social interaction is the driver of cognitive functioning. A lesson that can be learned from this social distancing episode is to no longer take social interactions for granted. Social interactions should be appreciated for their protective potential and interventions have to be developed to use this potential.

P8.2. Mental and social health consequences during pandemic in Poland

SZCZEŚNIAK Dorota, SENCZYSZYN Adrianna, MAĆKOWIAK Maria, MACIASZEK Julian, CIUŁKOWICZ Marta, MISIAK Błażej, RYMASZEWSKA Joanna

Wrocław Medical University, Wrocław, Poland

The concept of social health and its link to mental health has gained particular importance in the last year as the whole world adapts to life with a pandemic in the background. In Poland, a cross-sectional study was performed nationwide (n=2039) in the initial stage of the pandemic (March and April 2020) among the general population. However, due to the small percentage of elderly people (also those with dementia) among the respondents, additional data were collected based on individual interviews in the qualitative research approach.

Almost half (49%) of the respondents believed that fear for physical health had a negative effect on their mental health. 55% of the surveyed people showed clinically relevant psychopathological symptoms (GHQ-28 total >24). Moreover, as many as 61% felt the negative consequences of physical distance such as loneliness and feeling of isolation from the world and close people. These social health negative effects such as loneliness were perceived significantly more often by women. What is more, those who were quarantined showed significantly more psychopathological symptoms such as anxiety and insomnia. Preliminary results from the interviews with the elderly and their caregivers showed that social health consequences (feeling of isolation and loneliness) are more visible among older people, and negative emotional consequences such as anxiety, fear for the health of their relatives, frustration, fear for the future are related to caregivers. Moreover, people with dementia and their caregivers indicated that the situation of social isolation resulting from the pandemic had a significant, negative impact on their independence and contributed to faster cognitive deterioration.

The obtained results illustrate the relationship between psychological responses and social health consequences under special conditions, living in times of a pandemic. Thus, setting out the challenges that the world is currently facing, regardless of the country in which we live.

P8.3. Allowing visitors back in the nursing home during the COVID-19 crisis: a Dutch national study into first experiences and impact on well-being

GERRITSEN Debby1, VERBEEK Hilde2, BACKHAUS Ramona2, DE BOER Bram2, KOOPMANS Raymond1, HAMERS Jan2

1Radboud University Medical Center, Nijmegen, Netherlands, 2Maastricht University, Maastricht, the Netherlands

Objective: The restrictive measures to prevent and control COVID-19 infections in nursing homes have had an enormous impact on resident well-being and pose dilemmas for staff. Following a specifically developed national guideline, nursing homes could guardedly re-open for visitors starting May 11. We will report the first findings on how the guideline was applied in the local context; the compliance to local protocols; and the impact on well-being of residents, their family carers, and staff.

Methods: We conducted a mixed-methods cross-sectional study among the first 26 nursing homes that were permitted to allow visitors in their facility again. Data collection consisted of an electronic questionnaire, telephone interviews, analyses of documentation (i.e., local visiting protocols), and data of a WhatsApp group of contact persons.

Results: Local protocols varied, for example regarding the use of personal protective equipment, and location and supervision of visits. At large, experiences were very positive. All participants mentioned the added value of personal contact between residents and their loved ones and indicated a positive impact on well-being. Compliance with local guidelines was sufficient to good. No new COVID-19 infections were reported during this time.

Conclusions and Implications: Our results indicate the value of family visits in nursing homes and their positive impact. Based on these results, the Dutch government has decided to allow all nursing homes in the Netherlands to cautiously open their homes using the guidelines. More research is needed on impact and long-term compliance.
P8.4. Community services for people with dementia and their caregivers: “We deal well during COVID-19 but “it is time to restart face to face meeting”

CHATTAT Rabih1, VAIENTI Francesca2, CELLI Marika3, DE CAROLIS Stefano3, ROMERSA Giorgio2, GRAZIANI Manuela4

1University of Bologna, Bologna, Italy, 2Alzheimer Society, Rimini, Italy, 3Centro per i disturbi cognitive e demenze, Rimini, Italy, 4Azienda Servizi alla Persona- Valenti Marechla, Rimini, Italy

Background: The spread of COVID-19 in Italy had a significative impact on all services for people with dementia and their caregivers. Attention had been focused on nursing home, while services for community dwelling people with dementia had been less considered. In the area of Rimini (Italy) a plan had been developed in the last years aimed at ensuring an open access space (such as meeting center, meeting place and alzheimer’s café) are distributed in urban and rural areas and where people with dementia and their caregivers can meet and receive advice, interventions and support. The project involves health care and welfare agencies and the local Alzheimer society. After the onset of Covid and the related restriction, people with dementia and their caregivers experience isolation, loneliness and lack of support.

Objectives: In this study we will report about actions undertaken during the lockdown period and beyond from march to july, and the feedback from people with dementia, caregivers and staff about the benefit as well as suggestions for the next phase which will start in september 2020.

Methods: A qualitative approach had been used, using interview, whatsapp feedback, narrative stories from people with dementia, caregivers and staff.

Results: For the people with dementia and their caregivers the opportunity to be involved in online meetings and activities by the staff, already known, had been highly appreciated. The possibility to meet, to receive advice and tutorials for activities at home had been perceived as a supportive during the lockdown period. Since June, when restrictive measures start to be reduced, people with dementia and caregivers express a sense of fatigue and ask for face to face meeting.

Conclusions: The online activities offer a good support during the lockdown period and had been appreciated even if they cannot completely substitute the face to face meeting and direct interaction. In the future a balance should be found to combine both approaches.

This session is organised by INTERDEM.

P9. Psychosocial interventions

P9.1. Can the Meeting Centre Support Programme reduce the burden of stigma among people with cognitive deficits?

LION Katarzyna1, SZCZEŚNIAK Dorota2, EVANS Shirley3, EVANS Simon3, SAIBENE Francesca Lea4, D’ARMA Alessia5, SCOROLLI Claudia6, FARINA Elisabetta4, BROOKER Dawn7, CHATTAT Rabih5, MEILAND Franka6, DRÖES Rose-Marie6, RYMASZEWSKA Joanna2

1Menzies Health Institute Queensland, Griffith University, Brisbane, Australia, 2Department of Psychiatry, Wrocław Medical University, Wrocław, Poland, 3Association for Dementia Studies, University of Worcester, Worcester, United Kingdom, 4IRCCS Fondazione Don Carlo Gnocchi, Milan, Italy, 5Department of Philosophy and Communication Studies, University of Bologna, Bologna, Italy, 6Department of Psychiatry and Department of Research and Innovation, Amsterdam University Medical Centers, VU University Medical Center, GGZ inGeest, Amsterdam, Netherlands

Introduction: Although the issue of stigmatisation in dementia is widely discussed around the world, studies investigating the individual experience of people with dementia are lacking.

Aim: This project aimed to a) evaluate the level of stigmatisation across Poland, Italy and the United Kingdom, b) identify corresponding factors and c) assess the role of the Meeting Centre Support Programme (MCSP) in decreasing stigmatisation among people with dementia and mild cognitive impairment (MCI).

Materials and methods: A pre/post-test control group study design compared outcomes for 114 people with dementia and MCI in Italy, Poland and the UK who attended the MCSP or usual care (UC). The stigmatisation level was assessed with the Stigma Impact Scale: neurological impairment (SIS) at two points in time, 6 months apart.

Results: The level of stigmatisation (SIS) among participants varied from 2 to 65 (median = 33.5; Q1 = 27; Q3 = 41). People from the UK experienced a higher level of stigmatisation than people in Italy and Poland. Stigmatisation level negatively correlated with social support (rho = -0.42, p = 0.000) and life quality (rho = -0.39, p = 0.000). In Italy, stigmatisation was significantly lower (p=0.02) in the MCSP group following the intervention. Social Isolation level increased significantly (p=0.05) in the UC group after 6 months in Poland. Social Rejection level significantly raised (p=0.03) over time in the MCSP in the UK. Statistical analysis did not show any significant differences for 3 countries combined.

Conclusions: The experience of stigma by people with dementia and MCI is complex. There are country specific contexts and mechanisms. There is still a need for more detailed investigation into stigmatisation experience in different cultures/countries with a more sensitive measuring tool dedicated for people with dementia.
cognitive impairment. The role of psychosocial interventions in reducing the burden of stigma requires further investigation.

P9.2. Development of a theory of change for an intervention aimed to improve sleep of people with dementia in nursing homes

HALEK Margareta1, HYLLA Jonas1, BERG Almut4, EGGERS Daniela4, MEYER Gabriele4, KÖPKE Sascha3, DICHTER Martin1

1German Center for Neurodegenerative Diseases (DZNE), Witten, Germany, 2School of Nursing Science, Witten/Herdecke University, Witten, Germany, 3Institute for Health and Nursing Science, Medical Faculty, Martin Luther University Halle-Wittenberg, Halle, Germany, 4Institute of Social Medicine and Epidemiology, University of Lübeck, Lübeck, Germany, 5School of Public Health, Bielefeld University, Bielefeld, Germany, 6Institute of Nursing Science, University Hospital of Cologne, Köln, Germany

Background: The literature suggests low to moderate effectiveness of complex psychosocial interventions to reduce sleep disturbances in people with dementia (PwD) living in nursing homes. There is a lack of theory-driven multicomponent interventions and it is still unclear which components are most effective. More information about causal assumptions to create a better theoretical understanding of the intervention is needed.

Objectives: To develop a Theory of Change (ToC) that describes the causal assumptions for reducing sleep disturbances in people with dementia living in nursing homes.

Design and Methods: The ToC approach is a participatory method in intervention development to generate knowledge about how, why, and under which circumstances interventions can be effective. We conducted two expert workshops (n=16), a subsequent expert survey (n=12), a systematic literature review, and expert interviews (day and night nurses).

Results: Our systematic review indicates a low to moderate effectiveness of physical activities, staff training and bedtime routines. The conducted workshops within the ToC pointing out that a complex intervention needs to address staff, management and culture of nursing homes. Intermediate goals like “individual knowledge on people with dementia is available”, “a specific institutional concept to promote sleep is implemented”, “person-centred care is implemented” and “sleep preferences of person with dementia are fulfilled” were defined. All intermediate goals were rated as relevant or highly relevant in the expert survey. Based on the ToC, the new multicomponent sleep intervention includes theory-driven components and will be now tested in a clinical trial.

Conclusions: The ToC model displays how a complex psychosocial intervention is likely to be effective in reducing sleep disturbances and meeting sleep preferences of PwD in nursing homes. It defines the intervention elements and the requirements for a successful implementation. The ToC also provides a theoretical framework for planning a process evaluation along our evaluation study.

P9.3. Implementing two evidence-based eHealth interventions for caregivers of people with dementia: an evaluation of myinlife and partner in balance a municipality context

CHRISTIE Hannah1, BOOTS Lizzy2, TANGE Huibert3, VERHEY Frans2, DE VUGT Marjolein2

1Alzheimer Center Limburg, Maastricht, Netherlands, 2Department of Psychiatry and Neuropsychology and Alzheimer Centre Limburg, School for Mental Health and Neurosciences, Maastricht University, Maastricht, Netherlands, 3Department of Family Practice, CAPHRI School for Public Health and Primary Care, Maastricht University, Maastricht, Netherlands

Background: Evidence-based eHealth interventions for caregivers of people with dementia are rarely implemented into practice. Due to policy and innovation incentives regarding (dementia) caregiving and prevention, municipalities are being considered as a promising context to implement these interventions. This study examines the implementation of Myinlife and Partner in Balance, two evidence-based eHealth interventions for caregivers of people with dementia, in eight municipalities in the Euregion Meuse-Rhine. The aims were to evaluate the implementation and investigate determinants of successful implementation.

Methods: This study took place in the context of the euPrevent Senior Friendly Communities project. This study collected the interventions’ usage data, administered Partner in Balance coach evaluation questionnaires, and interviewed municipality officials. The interviews were conducted with an interview guide based on the Measurement Instrument for Determinants of Implementation (MIDI). The different types of data were integrated and mapped to analyze which implementation determinants were linked to successful implementation.

Findings: Implementation was considered successful in five of the eight municipalities. However, only three municipalities planned to continue the implementation of Partner in Balance, while none planned to continue the implementation of Myinlife. Successful implementations were linked to implementer self-efficacy and ownership, which were not as present in unsuccessful implementations. For Myinlife, there was insufficient in-person interaction to foster a sense of ownership in the implementing municipality. For Partner in Balance, implementers experienced uncertainties about their implementation capabilities.

Conclusions: The implementation of eHealth interventions to support caregivers of people with dementia in municipalities was promising. These findings on sense of ownership and self-efficacy as important implementation determinants will give direction to future implementation packages for Myinlife and Partner in Balance. These intervention-specific implementation packages will facilitate sustainable
Implementation of these interventions and contain concrete guidelines for the municipal implementation team and the implementing health care organizations.

P9.4. What are we measuring when we test non-drug interventions in MCI and mild dementia? A scoping review

COUCH Elyse, CO Melissa, LAWRENCE Vanessa, PRINA Matthew
King's College London, London, United Kingdom

Background: Non-drug treatments are an important aspect of dementia care, they are often a safe alternative to drug treatments. When testing non-drug treatments there are a wide variety of outcome measures for researchers to choose from. However, this diverse use of outcome measures makes it difficult to make meaningful comparisons between treatments.

Aim: This study aimed to systematically map which outcome measures are being used in studies testing non-drug treatments in mild cognitive impairment and dementia.

Methods: This study was a scoping review of randomised controlled trials of non-drug treatments for mild dementia and mild cognitive impairment. EMBASE, Psych Info, Medline and the Cochrane Register of Controlled Trials were searched to identify relevant papers. We extracted which outcome measures were used by the included studies and explored the trends in the use of outcome measures by type of intervention, country and year of publication.

Results: We identified 91 eligible studies. We extracted 358 different outcome measures, 22% (78) were used more than once. Cognition was the most measured domain with the MMSE being the most common outcome measure. Cognition remained the most consistent domain measured over time, over all types of intervention and country. Despite people living with dementia and their caregivers rating quality of life being the most important outcome, quality of life was only measured by 14 studies, and the use of quality of life measures had decreased over time.

Discussion: Our findings show an inconsistency in the use of outcome measures, with cognition being used over other important measures. To be able to make meaningful comparisons between non-drug treatments researchers should be clear on what benefits they can expect their treatments to produce, and choose high quality outcome measures which can capture these benefits.

P9.5. A feasibility study of a randomised control trial to investigate the individual Cognitive Stimulation Therapy (iCST) application for people with dementia

RAI Harleen, SCHNEIDER Justine, ORRELL Martin
Institute of Mental Health, University of Nottingham, Nottingham, United Kingdom

Introduction: There is a lack of resources for the mental stimulation and engagement of people with dementia. Cognitive Stimulation Therapy (CST) is a non-pharmacological, group treatment for people with dementia and has shown to improve cognition and quality of life (QoL). Recently, an individual version of CST (iCST) has been developed which is delivered by a carer at home, and benefits the relationship quality of the dyad, and the QoL of carers. Technology-based interventions have also demonstrated some promising effects on the cognition and well-being of people with dementia and therefore, a touch-screen version of iCST (the iCST app) has been developed.

Aims: to evaluate the feasibility of conducting a full-scale Randomised Controlled Trial (RCT) with the iCST app compared to a treatment as usual (TAU) control group.

Methods: a multi-centre, pragmatic, single blind feasibility trial was undertaken in the United Kingdom (n = 43). Dyads were randomised to the iCST app intervention or TAU group for 11 weeks. Feasibility outcomes included recruitment, and retention rates, intervention fidelity and usability, and acceptability of the outcome measures. A total of three semi-structured, post-trial interviews were conducted.

Results: Twenty-one dyads were randomised to the iCST app intervention and 22 to the TAU group with high retention rates. Slow recruitment was due to the specific, technology-related inclusion criteria. Intervention fidelity was lower than expected and was likely due to a lack of sufficient, tailored content. Findings also indicated improvements in the QoL of carers after using the iCST app. No other effects were detected.

Conclusions: Considering the positive attitudes of people with dementia and carers towards the iCST app and the promising results from the feasibility trial, it is recommended to conduct a large-scale RCT with a refined version of the iCST app and minor modifications to the study design and process.

P10. Training of care professionals

P10.1. What works is what matters: how care workers in care homes learn to care for people living with dementia

LATHAM Isabelle1, BROOKER Dawn1, MITCHELL Theresa2, DE VRIES Kay3
1Association for Dementia Studies, University of Worcester, Worcester, United Kingdom, 2University of Worcester, Worcester, United Kingdom, 3De Montfort University, Leicester, United Kingdom
The Dementia Champions Programme was commissioned as part of Scotland’s first dementia strategy in response to the poor hospital care experiences people living with dementia were experiencing. Funded by the Scottish Government in collaboration with NHS Education for Scotland, and the Scottish Social Services Council, this educational programme has been running since 2011. The programme aims to provide enhanced dementia care education to qualified health and social care professionals to support them to champion and lead positive change in their hospital care settings. Over 1000 health and social care professionals have completed the programme to date.

This presentation will outline findings from the longitudinal pre and post-test intervention data collected from 524 participants. The findings show that the programme had a statistically significant positive effect on participants’ knowledge of dementia, approaches to dementia care and confidence in their ability to achieve the learning outcomes of the programme. It will also present the findings of a doctoral study that used grounded theory to illuminate the educational, professional and practice impact of the programme on participants.

Key elements of success are attributed to the programme’s clear educational and theoretical underpinning, a human rights focus to care provision and consistent focus on the future role of participants as dementia champions. The champions’ programme directly challenges stigma and aims to reconceptualise what it is to experience dementia. The participation of people with dementia and family carers plays a vital role in achieving this.

The findings have implications for how dementia care is taught in both the first and continuing professional education of all health and social care staff.

P10.3. Developing person-centred care practice around the world through staff training and development

PERRY Wendy
Dementia Services Development Centre, Stirling, United Kingdom

The Best Practice learning programme has been running now for twelve years, and has been used to develop the knowledge, skills and practice of over 12,000 care staff and volunteers in the UK. Since 2017 the Dementia Services Development Centre (DSDC) in the University of Stirling has been partnering with the Jockey Club Centre for Positive Aging (JCCPA) to bring the Best Practice in Dementia Care programme to Hong Kong. Following the translation of materials into Cantonese, JCCPA staff were trained by the DSDC to develop Best Practice facilitator training courses. Over the past three years the JCCPA has used the Best Practice Programme to train over 1200 health and social care staff in Hong Kong. Researchers from the Chinese University of Hong Kong, Jockey Club Centre for Positive Ageing and the University of Stirling looked at the effects of the Best Practice programme on staff knowledge, attitude, sense of competence related to dementia care and job satisfaction and explored how the staff
dementia care attitudes and practices have been influenced immediately following training and again at a
twelve month follow up.

This presentation by the DSDC will review and discuss the findings and provide a short video interview
between Wendy Perry, Head of Learning and Development at the DSDC and Dr. Kenny Chui, Chief
Training Consultant and Dementia Care Specialist who led the project for the JCCPA in Hong Kong. They
will discuss the challenges and rewards presented by translating a care training model across cultures,
and how reflective learning can be used to build empathy and person-centred practices.

P10.4. Who is in charge? Exploring the multiple roles involved in supporting people with
dementia and dysphagia

COLLINS Lindsey†, OYEBODE Jan†, HART Andrew†, LESLIE Paula‡
†University of Bradford, Bradford, United Kingdom, ‡University of Central Lancashire, Preston, United Kingdom

Introduction: Eating and drinking are essential for life; play a key role in solidifying people's identities as
part of social groups; and have symbolic and moral significance in different cultures and societies. People
living with dementia are at an increased risk of having eating, drinking and swallowing difficulties
(dysphagia). Multiple health and care professionals, as well as family members are involved in supporting
people living with dementia who experience dysphagia.

Methods: This qualitative study used interviews, focus groups and structured observations (using
Dementia Care Mapping) to look at the different roles and perspectives involved and how differences of
opinions are resolved or responded to. Inductive thematic analysis was used to identify themes that
represent the experiences and areas of importance for participants.

Results: A total of 70 individuals participated in the study, including people living with dementia, family
carers, care home staff and Speech and Language Therapists. 31 interviews were carried out along with
two focus groups and 35 hours of Dementia Care Mapping observations.

Results: Thematic analysis of the data highlighted the challenges of multiple perspectives, including the
uncertainty of roles and responsibilities; how decisions are made; how disagreements are managed; and
the different perspectives different groups of people bring to the table, specifically knowing the person
versus knowing about dysphagia.

Discussion and conclusions: The findings from this study highlight that supporting people living with
dementia and dysphagia requires careful consideration of a range of important factors. It is important to
have clear roles, responsibilities and channels of communication between people living with dementia,
family members, care home staff and healthcare professionals. Care professionals will benefit from this
knowledge to aid them in better supporting people living with dementia and dysphagia, particularly in
residential care facilities.

P10.5. "Listen to our voice too!" - the training needs of care providers in the residential care
homes

CHUI CHI MAN Kenny
The Chinese University of Hong Kong, Hong Kong, Hong Kong

Chi dai zheng, the term for dementia used across parts of Asia under the Chinese sphere of influence,
carries a negative connotation of idiocy that has long fuelled negative stereotypes of people with the
condition. In such cultures, how people with dementia perceive themselves, how care staff perceive them
as well and how training sessions addressing their self-perceptions can influence the care provided by
staff in residential care homes. Indeed, how the care staff and people with dementia perceive each other
can significantly affect the daily quality of life of both parties (Hubbard, Tester, & Downs, 2003).

In my research findings, the residents with dementia did not perceive themselves as being ‘demented’
and were confused by that label. By contrast, perpetuating the common stigma, the care staff perceived
the residents as being ‘demented’, desolate troublemakers. They felt frustrated and exhausted with caring
for the residents, whom they described as naughty children or psychiatric patients. Taken together,
divergent perceptions between residents and the care staff affected general interpretations of people with
dementia, which puzzled residents about their situations in the residential care homes. Revealing that the
psychological needs of people with dementia and the care staff are under-recognised in the dominant
discourse on dementia, the findings suggest that improving familiarity with the reasons behind those needs
and offering training in understanding the self-perceptions of people with dementia were crucial. In the
training sessions geared towards elucidating the self-perceptions of residents, the care staff were able to
reflect upon their practices and, in turn, develop a more empathetic understanding of people with
dementia. Such findings suggest a new standpoint from which to understand people with dementia and
promote the development of training in dignified dementia care that involves the ASK model (A-Attitude;
S-Skill; K-knowledge) and a proper dementia care attitude, called “DemenTitude”.

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P11. AI approaches for dementia research, diagnosis and treatment

P11.1. Cloud-based simulation for personalised diagnosis and therapy

RITTER Petra
Charité University Medicine Berlin

The Virtual Brain Cloud is a European consortium that builds an e-infrastructure for processing sensitive data in the cloud. The goal is to integrate numerous data types to run brain simulations and to build predictive disease models and discover disease mechanisms. GDPR requires high standards for the sharing and processing of sensitive data – such as brain scans – to protect the rights of the data subjects. Organizational and technical measures need to be in place to provide appropriate data protection. TVB-Cloud aims to fill the existing gap, i.e. the lack of platforms that can offer the degree of protection required. To achieve this we have formed an interdisciplinary team of engineers, scientists, legal experts and patient representatives.

P11.2. Mapping mechanisms in AD and PD

HOFMANN-APITIUS Martin
Germany

Abstract not provided

P11.3. Biomarkers of healthy ageing from brain imaging data and prospective applications in AD

JIRSA Viktor
Ins Aix Marseille University, France

The term “functional connectivity” refers to connected patterns of activation in different areas of the brain, as observed using brain imaging techniques such as functional MRI, EEG or PET scans. Brain functional connectivity is inherently dynamic and is directly linked to our behaviour and neural activity. Interestingly, research suggests that fluctuations in functional connectivity may provide crucial information about our brain state during development, ageing, or during the progression of neurological disorders. However, further studies are needed to accurately model these fluctuations under different resting-state and activity conditions, and to understand how these functional connectivity models vary from person to person. Here, we present our causal modeling approach to analyze dynamic functional connectivity in The Virtual Brain, showing how this platform can be used to explore personalized brain models constructed from individual brain scans. When applying our analysis to an fMRI dataset in healthy elderly individuals, we find that the dynamic functional connectivity tends to slow down, becoming less complex and more random with increasing age. All these effects are strongly associated with age-related changes in cognitive performance. We establish the individual predictive power of our approach and provide a perspective on how functional connectivity networks change in brain disease.

This session is organised by the H2020 Virtual Brain Cloud project

P12. Ethnic minorities

P12.1. The care situation of people with dementia in Romania

TUDOSE Catalina
Societatea Română Alzheimer, Romania

Dementia is a major society challenge in Romania as a consequence of the notable demographic change in the last decades simultaneously with the decrease in birth rates. Due to an increase in life expectancy the number of people with dementia was predicted to rise by 50% from 2015 to 2030 in Eastern Europe. In Romania these problems are joined by the aging of the generations corresponding to the period 1950-1970 and their replacement by the numerically reduced generations after 1970, as well as the migration of the young population that comes to complete the worrying demographic picture.

According to estimates by the Organization for Economic Cooperation and Development (OECD, 2013), in Romania, the prevalence of the disease is 4.7% for those over 60 years and at least 300,000 older adults are currently affected by dementia.

In university centres and urban areas there are developed the extreme poles of the dementia care needed network, namely diagnosis services and nursing home care facilities, many of them functioning on private bases. There is a shortage of comunitary services in between, i.e. day centres and special care units, support services for families and carers and there is a low coordination of those available. We can mention the high level of knowledge and skills of the specialists in psychiatry, neurology and geriatry, but shortage of neuropsychologists and lack of involvement of the general practitioners. The primary diagnosis is predominantly done in the medium and medium/severe stages of dementia. The quality of dementia care is behind the European standard, especially in rural areas. There is a strong need for developing and
implementation of a national dementia strategy, in order to enhance the quality of life for people with dementia and their informal carers.

**P12.2. Dementia diagnostics and care for older migrants in the Netherlands: work in progress**

GOUDSMIT Miriam1, VAN CAMPEN Jos2, PARLEVLIET Juliette2, SCHMAND Ben3

1OLVG Hospital, Netherlands 2Amsterdam University Medical Centre, Netherlands, 3University of Amsterdam, Netherlands

In 2020, more than 1.3 million (7.7% of the population) first generation migrants from non-western countries (mainly from Turkey, Morocco, Surinam and Indonesia) live in the Netherlands, mostly in the big cities. Although these migrants are relatively young compared to the greying native Dutch population, our research found a dementia prevalence 3-4 times higher than in native Dutch. We notice a continuing increase in referrals for dementia diagnostics to our hospital-based memory clinic in Amsterdam. Limited dementia awareness and knowledge, poor proficiency of the Dutch language, low educational level, illiteracy and different cultural expectations are barriers to a timely and valid dementia diagnosis in these groups. Also, care professionals sometimes lack knowledge and experience with these barriers.

We developed new and validated existing dementia screening instruments such as the Cross-Cultural Dementia screening, RUDAS and IQCODE for these older migrants. We bridged the gap between primary and secondary care by educating general practitioners in the region about appropriate screening tests and by starting local outpatient clinics. This has led to a formalized care path in the Amsterdam West neighborhood.

Now, the accent should shift from diagnostics to care. Care facilities such as home care, day care, and nursing homes where Turkish or Moroccan is spoken and where diet preferences are available, are still sparse. Furthermore, both patients/older migrants and their children expect that their families care for them, despite the children’s increasing westernization. This regularly leads to overburdened informal care givers. Also, mental health care in their own language and close to their homes, is a challenge. Finally, end-of-life care for older migrants also deserves special attention, because many prefer more covered communication, with more room for hope and religious rituals in the process of passing away.

**P12.3. Survey of memory services regarding provision for people from minority ethnic groups**

MUKADAM Naaheed

University College London

The UK has a sizeable minority ethnic population (15% of the whole population and 39% of the London population). A number of national guidelines regarding dementia assessment and management have been published and these include considerations of cultural and linguistic diversity when assessing people with cognitive complaints. We conducted a review of national dementia guidelines with regards to provision for people from minority ethnic groups. We then used these guidelines and consultations with the NHS England dementia network to design a questionnaire about current memory service practice and provision for people from diverse groups. We sent the questionnaire to all memory services in England and Wales and followed this up with two reminders from April to August 2020. We received a 10% response rate and there was great diversity in the proportion of minority ethnic patients seen in each memory service. Most services were aware of the need to provide interpreters and the different culturally adapted assessment tools that were available. Problems with communicating via letters written only in English were raised as potential barriers to assessment and practice varied widely in terms of what translated resources were available for patients and how much post-diagnostic support could be offered to people from diverse backgrounds. This is the first time such a survey has been completed and it provides a useful initial step in improving service provision to make it more equitable for people from all backgrounds. Response bias is a potential limitation and the COVID-19 pandemic is likely to have affected response rates due to redeployment of staff.

**P12.4. EU-Atlas on dementia & migration**

MONSEES Jessica, SCHMACHTENBERG Tim, THYRIAN Jochen René

German Center for Neurodegenerative Diseases

Background: The proportion of people with migration background aged 65 years or older increases, therefore it can be assumed that the proportion of people with migration background with dementia will increase as well. So far, data on prevalence for dementia in people with migration background on a European level are scarce and it is not known how countries in Europe target the topic of dementia and migration in their national dementia strategies and migrant organizations as well as in national guidelines for diagnostic and therapy.

Research question: Prevalence data on dementia and migration will be determined for the countries of the European Union (EU), the European Free Trade Association (EFTA) and the UK. Guidelines regarding diagnosis, treatment and care, national dementia strategies, healthcare services, communities and migrant organizations will be evaluated regarding dementia and migration.

Method: Prevalence data will be estimated based on dementia prevalences of the country the people are living in. Interview with experts, literature analysis, and expert workshops will be used to analyze guidelines, national dementia strategies, healthcare services, communities and migrant organizations.
Expected results: An extensive collection of information about dementia and migration in the different European countries, depicting prevalences, guidelines on therapy and diagnostic, healthcare services and dementia as a topic of interest in migrant organizations will be provided. From this collection, the EU-Atlas on dementia and migration will be created.

Discussion: Obtaining this information can help to uncover gaps in the healthcare systems and communities on a European level. This can serve as a starting point to see where action must be taken and may therefore lead to better healthcare for people with migration background with dementia.

This session is organised by DZNE.

P13. Diagnosis and disclosure

P13.1. The diagnostic and treatment challenges of behavioral and psychological symptoms in Alzheimer’s disease; a qualitative study in memory clinic practice

PAPMA Janne1, EIKELBOOM Willemi1, COESMANS Michiel1, OSSENKOPPELE Rik2, VAN DEN BERG Esther1
1Erasmus MC, Rotterdam, Netherlands, 2Amsterdam UMC, Amsterdam, Netherlands

Introduction: Timely recognition and treatment of behavioral and psychological symptoms in dementia (BPSD) may benefit quality of life, caregiver burden, and delay disease progression of community-dwelling Alzheimer’s disease (AD) patients. In this qualitative study we examine the experiences of memory clinic physicians with the recognition and management of BPSD in AD.

Methods: Semi-structured interviews were held with 10 physicians (6 neurologists, 4 geriatricians) employed at memory clinics of academic or general hospitals in the Netherlands. Two independent researchers coded verbatim transcripts of the interviews, followed by a consensus meeting on themes.

Results: Preliminary results indicate substantial variability in how memory clinic physicians recognize and diagnose BPSD in AD. Themes are: 1. Prevalence of BPSD in early stages of AD; e.g. ‘BPSD is more often present in late stages of AD [...]’ vs. ‘I see this often [in the memory clinic], I think these are the main problems people with AD face’). 2. Systematic assessment; some physicians consider it part of clinical work-up to assess behavioral changes while others do not touch upon BPSD. 3. Barriers for assessment; e.g. a lack of time, and inability to observe BPSD occurring at home in a memory clinic setting. Treatment and management of BPSD in AD also differed greatly. Themes are 1. Treatment type; Two physicians use a person-centered non-pharmacological approach, others refer patients with BPSD to a case-manager or psychiatrist, or treat ‘problematic’ behaviors with psychotropic drugs. 2. Capabilities; some physicians experience managing BPSD in AD as very difficult, while others are confident about their capabilities.

Conclusion: There are remarkable differences in the recognition and management of BPSD in AD patients visiting memory clinics in the Netherlands. Considering the potential benefit of early recognition and treatment, a first step is discussing standardization of optimal diagnosis and treatment strategies for BPSD in memory clinics.

P13.2. BASIC – a new case finding instrument for dementia for use in clinical settings

JØRGENSEN Kasper1, NIELSEN T. Rune1, NIELSEN Ann1, WALDORFF Frans Boch2, WALDEMAR Gunhild1
1Danish Dementia Research Centre, Copenhagen, Denmark, 2University of Copenhagen, Copenhagen, Denmark

Objective: Previous research indicates that combining cognitive assessment with informant and self-report improves accuracy in dementia case-finding. The aim of this study was to develop and validate a new case-finding instrument for dementia for use in clinical settings inspired by existing instruments and including elements from validated questionnaires.

Methods: According to focus group interviews with general practitioners and district nurses, the instrument should: 1) be broadly applicable in general practice and memory clinics, 2) easily administered, 3) have good discriminative validity, 4) be relatively free from educational, age and gender bias, and 5) should not contain unnecessarily confrontational items.

The Brief Assessment of Impaired Cognition (BASIC) includes 1) Self-report, 2) Informant report, 3) Supermarket Fluency and 4) Category Cued Memory Test (score range 0-25). It can be administered in 5 minutes. BASIC was prospectively validated in Danish memory clinics. Patients consecutively referred from general practice were tested at their initial visit prior to diagnosis. Control participants were primarily recruited among participating patients’ relatives. Expert clinical diagnosis was subsequently used as reference standard for the classification accuracy of BASIC.

Results: BASIC was found to have high discriminative validity (sensitivity .95, specificity .98) for dementia (n = 122) versus socio-demographically matched control participants (n = 109). In comparison, the MMSE had 0.82 sensitivity and 0.90 specificity. Limiting the discriminative validity analysis to MCI (n = 42) caused a relative attenuation of the classification accuracy of BASIC (sensitivity 0.86, specificity 0.89) whereas
the discriminative validity of MMSE was further reduced (sensitivity 0.61; specificity 0.72). Performance on BASIC is unaffected by education and only slightly affected by age and gender.

Conclusion: BASIC is a brief, efficient and valid case-finding instrument for dementia in a memory clinic setting. Further cross-validation in a general practice setting has been initiated.

P13.3. Adjustment to test, risk and diagnostic disclosures in people with mild cognitive impairment: an observational cohort study
SAUNDERS Stina, RITCHIE Craig, MUNIZ-TERRERA Graciela, RUSS Tom
University of Edinburgh, Edinburgh, United Kingdom

Introduction: Mild cognitive impairment (MCI) is a state between normal healthy ageing and dementia with an uncertain prognosis in terms of its risk of progression into dementia. This creates a complex dynamic between what is communicated to the individual about their condition and how the individual perceives the information conveyed to them.

Aim: The aim of the study is to understand whether the way information is conveyed to patients with newly identified MCI at memory assessment services could have an impact on the patients’ clinical outcomes and possibly lead to an altered prognosis. We focus on specific outcomes for the individual – changes in cognition, anxiety, psychological well-being and adjustment to illness in the short and long term.

Method: This is a longitudinal mixed methods study. The project has recruited 63 people (men = 25 (40%); women = 38 (60%)), from across five sites in the South East region of Scotland who had been referred to a memory assessment service with a clinical suspicion of MCI. These participants have been longitudinally assessed since June 2018 before and after they have been disclosed of memory assessment results. The study uses a battery of quantitative assessment measures as well as conducting semi-structured interviews with a subset of participants.

Results: Baseline assessments ran from June 2018 – July 2019 and all follow-up assessments will be completed by March 2021. We will be presenting baseline and two waves of follow-up data at the Alzheimer Europe conference (missing the last data point which will not have completed). Initial results show the concept of MCI is perceived with mixed feelings, with the immediate response to disclosure more positive and as time goes on, the initial perception shifting. The conference will provide an opportunity to discuss the impact of being informed of potential dementia risk on individuals.

P13.4. Improving the diagnosis of mild cognitive impairment in elderly individuals using a multifactorial automatic analysis of voice quality and prosody
THEMISTOCLEOUS Charalambos1, ECKERSTRÖM Marie2, LUNDHOLM FORS Kristina2, KOKKINAKIS Dimitrios2
1Johns Hopkins Medicine, Baltimore, United States, 2University of Gothenburg, Gothenburg, Sweden

Introduction: While the effects of cognitive decline on speech production of patients with Mild Cognitive Impairment (MCI) are not as extensively studied as other aspects of cognitive decline, recent studies show speech impairments in these individuals[1, 2]. Our previous work analyzed segmental and prosodic features of speech production and showed that vowel formant frequencies and vowel duration can distinguish patients-with-MCI from controls with 83% mean cross-validated accuracy[1]. This new research aims to identify whether voice quality and speech fluency distinguish patients-with-MCI from controls, to provide objective markers from speech and ultimately improve diagnosis.

Methods: 55 people participated in a Cookie theft picture description task from the Boston diagnostic aphasia examination; 26 patients-with-MCI and 29 controls from Sweden. The recordings were acoustically analyzed and measures of i. voice quality (i.e., breathy/creaky voice, spectral energy, dysphonia, articulatory effort, jitter, shimmer, harmonicity); ii. speech fluency (i.e., speech and articulation rate), and, prosody (mean fundamental frequency), were elicited from the recordings.

Results: Patients-with-MCI differ significantly from controls with respect to voice quality (breathy/creaky voice, cepstral peak prominence, center of gravity, shimmer); and speech fluency (articulation rate and averaged speaking time).

Discussion: Voice quality and speech fluency differentiate patients-with-MCI from healthy controls. An unexpected finding was that lower periodicity in spectra that corresponds to greater dysphonia distinguishes patients-with-MCI from healthy individuals. The acoustic measures presented can facilitate the automatic analysis of speech in the clinic quantifying speech production and ultimately provide accessible acoustic diagnostic markers of patients-with-MCI.

**P13.5. What can a diagnosis of dementia tell me? A call for more research into sub-types of dementia**

MACKELL Sean, QUAD Kevin, PALEY Gerry, GEGHEGAN Carmel, O'REILLY Ciara, ROCFORD-BRENNAN Helen


**Background:** The Dementia Research Advisory Team is a group of people living with dementia and carers/supporters who are involved in dementia-related research as co-researchers. These Experts by Experience influence, advise and work with researchers across Ireland to improve the quality and relevance of research. The team is supported by The Alzheimer Society of Ireland (ASI) and also contribute to ASI funding decisions. They work to influence change and ensure that real life experiences are considered in designing and implementing research. This another important aspect of Person Public Involvement (PPI) is research prioritisation i.e. setting the research question.

**Content:** Members of the Dementia Research Advisory Team are deeply concerned that a large portion of people who have a diagnosis of dementia do not receive any specific information about the sub-type of dementia they have. ‘Dementia’ is an umbrella term used to describe several progressive conditions affecting the brain so what does a diagnosis of dementia really mean for a person and their family? Similarly, many people are ‘diagnosed’ as having memory problems.

A diagnosis of ‘dementia’ does not bring about the much-needed specific information that will equip the person and their families to face their diagnosis. Certain sub-types remain in the shadows and are critically under-researched.

Members of the Dementia Research Advisory Team wish to discuss this issue and how it impacts them and their peers. They want to call upon the research community to continue and expand their crucial research into brain disease and different types of dementia so that people can benefit from much-needed clarity around their diagnoses.

**P14. Awareness campaigns**

**P14.1. Using our advocates’ voices to campaign for change: Pre Budget Submission 2020**

GERNON Lisa

*Alzheimer Society of Ireland, Dublin, Ireland*

“I was diagnosed with Alzheimer’s disease in 2012 after a five year struggle to get a diagnosis. Since then I have campaigned relentlessly so that politicians will change policy and people with dementia are better supported from their diagnosis onwards. But I’m still asking, still waiting and still struggling” Dr Helen Rochford Brennan, July 2019.

Helen, member of the Irish Dementia Working Group and Chair of the European Working Group of People with Dementia, spoke these words at the launch of The Alzheimer Society of Ireland (ASI) Pre-Budget Submission (PBS) 2020 ‘Dementia Supports Across Ireland – Still Asking, Still Waiting, Still Struggling’ in July 2019.

Each year, The Alzheimer Society of Ireland lobbies the Irish Government to ring-fence specific funding for supports and services in their budget for people living with dementia and those who care for them. This presentation will detail our campaign and how we developed it by collating the campaigning work that had been undertaken over the years by a number of people living with dementia and a family carer. We produced three in-house campaign videos to amplify the message of our PBS campaign to demonstrate to the Government, policy makers and the general public that people impacted by dementia are Still Asking, Still Waiting, Still Struggling for investment in dementia care.

We used their voices to highlight the urgency of the need for investment.

http://tiny.cc/2nq5oz – Dr Helen Rochford Brennan

This presentation will demonstrate how the effective use of advocates’ voices can be used to bring about real change.

Last year in Budget 2020 the Government announced funding for 10 additional Dementia Advisers, something we had been calling for many years. It is clear that the voice of those involved in the campaign had an impact, both on the public and on government decisions.

**P14.2. Increasing awareness of dementia amongst supermarket employees and its customers - the case of REMA 1000**

VAN DEN BOS Katrine, VAN DEN BOS Katrine

*Alzheimerforeningen, Copenhagen, Denmark*

Since 2016 Alzheimerforeningen (The Danish Alzheimer Association (DAA)) has partnered with REMA 1000 (a supermarket chain with over 300 supermarket stores in Denmark).
In 2020 the DAA launched an internal campaign using REMA 1000 employees to share their best advice and experiences on how to help people with dementia. The campaign was running on Rema 1000’s employee workspace (reaching 12,000 employees) and consisted of short videos of employees sharing their experience on how to interact with and help customers with dementia. The content was produced by the DAA and some of the content was also shared in DAA’s digital communication.

The annual prize 'Demensven', which is given for a remarkable effort to help people with dementia, was awarded to a REMA 1000 employee whom exercised a special focus on how to help customers with dementia, and bond with their families in case of challenges that may occur.

The Danish Dementia Friends Programme has a specific focus on engaging the private sector through strategic partnerships. Based on knowledge from the annual think tank for people with dementia, the DAA focuses on developing partnerships with the transport and retail industries. The approach is to offer tailor-made partnerships, where the focus is to give employees knowledge about how to adapt to customers with dementia. Supplying information on dementia to our partners’ using online learning platforms and intranet is essential.

In Denmark almost 10% of the Danish population is affected by Dementia either as living with dementia or as a caretaker. The DAA introduced its Dementia Friends program in 2015. The Danish Dementia Friends programme, also called ‘Demensven’ is highly inspired by the Alzheimer’s Society UK’s initiative Dementia Friends. The initial goal was to reach 100,000 Dementia Friends, that was accomplished in May 2019. Now the DAA is working towards engaging 500,000 Dementia Friends.

P14.3. Building an inclusive society: a national campaign led by France Alzheimer

GILLY Lorène
France Alzheimer's and related diseases, Paris, France

In 2019, for World Alzheimer’s Day (WAD), France Alzheimer and related diseases chose to focus its message on inclusiveness and the necessity for all citizens to take into consideration people living with dementia and their caregivers.

The main objective of this national campaign, which was designed to last long after WAD 2019, is to raise awareness among society and to dismantle stigmas around the disease and its consequences.

This campaign was built on three main axes:

- raising awareness and training the major national stakeholders (police and fire departments, railway operators, etc.), with the help of our nationwide network of 99 local organizations. It is essential that these actors of the everyday life are able to recognize, appease and support people living with dementia in their daily activities;
- broadcasting a unifying symbol of recognition to signal our support for people living with dementia. Since we began its broadcasting, it appears to be a useful tool to spread awareness and the necessity to show more support to people living with dementia and to their caregivers;
- inviting mayors of every French city to sign our pledge called “Alzheimer Caring City” and to engage in an inclusive approach. So far, more than 200 cities and/or departments (a form of local government) have signed our pledge and engaged since then in an active approach to facilitate in concrete terms the everyday life of people living with dementia and their families among their local communities.

With the active support of citizens, professionals and public authorities, France Alzheimer and related diseases strongly believes that, all together, we can build a more inclusive society for people with dementia and their family carers.

P14.4. Convincing the public that time really does matter in brain health

SCHELTENS Philip1, NOYCE Alastair2, GIOVANNONI Gavin3, BERG Daniela4, BROWN Laurie5, DIERICKX Kris6, FRISONI Giovanni7, HARDY John8, HEILBRON Karl9

1Alzheimer Center Amsterdam, Amsterdam, Netherlands, 2Wolfson Institute of Preventive Medicine, Queen Mary University of London, London, United Kingdom, 3Blizard Institute and Wolfson Institute of Preventive Medicine, Queen Mary University of London, Barts and The London School of Medicine and Dentistry, London, United Kingdom, 4Department of Neurology, Christian-Albrechts University of Kiel, Kiel, Germany, 5Institute for Governance and Policy Analysis, University of Canberra, Canberra, Australia, 6Centre for Biomedical Ethics and Law, Catholic University of Leuven, Leuven, Belgium, 7Centre de la Mémoire, University Hospitals and University of Geneva, Geneva, Switzerland, 8Department of Neurodegenerative Diseases, University College London, London, United Kingdom, 923andMe, Inc., Sunnyvale, CA, Sunnyvale, United States

Background: To maximize the potential for prevention and early intervention, the general public needs to understand the risk factors that can affect their brain health and how to maintain it. Dementia is not an inevitable part of ageing; however, awareness of this is low and the desire to learn about the risk of developing Alzheimer’s disease (AD) is hampered by a lack of conclusive biomarkers.[i] Adjustment of modifiable lifestyle factors in early- to midlife can significantly help to reduce the risk of developing a neurodegenerative disease.

Consensus development: A multidisciplinary, geographically representative group with expertise in dementia, AD, Parkinson's disease, genetics, epidemiology, public health, patient advocacy and ethics developed an evidence-based set of recommendations to prepare a framework for a preventive approach to neurodegenerative diseases.[ii]
Implementation: The group produced 18 recommendations, of which 5 related to health promotion. Encouraging behaviours at all ages that help to improve brain health is crucial. Public health budgets must be provided and protected to improve public understanding of brain health and promote a positive approach that helps to reduce the risk of neurodegeneration.

Implications: Policymakers and public health bodies are well placed to provide a supportive environment, including national guidance and legislation that empowers individuals to make important lifestyle changes. Organizations working for change can collaborate to encourage the general population to adopt brain-healthy lifestyles and potentially reduce the risk factors and the likely progression to a disease diagnosis. Further research is needed to establish which lifestyle factor modifications would bring the greatest risk reduction.


P14.5. Age-friendly policies in a cross-national setting: are communities ready for healthy ageing?

SCHICHEL Mignon1, VEESTRA Marja2, KEMPEN Gertrudis3, DE VUGT Marjolein4, VERHEY Frans2

1Maastricht University, Maastricht, Netherlands, 2Department of Psychiatry and Neuropsychology and Alzheimer Center Limburg, School for Mental Health and Neuroscience (MHeNs), Maastricht University Medical Centre, Maastricht, Netherlands, 3Department of Health Services Research, Care and Public Health Research Institute (CAPHRI), Faculty of Health, Medicine and Life Sciences, Maastricht University, Maastricht, Netherlands, 4Department of Psychiatry and Neuropsychology and Alzheimer Center Limburg, School for Mental Health and Neuroscience (MHeNs), Maastricht University Medical Centre, Maastricht, Netherlands

Background: In several Western European countries, local communities have a responsibility in supporting older people and informal caregivers, including people with mental health problems such as dementia. Cross-border collaboration could benefit communities due to their similar demographic profiles by exchanging best practices. However, little is known about the local community policies on public health with respect to dementia and the prevention of depression for older people and their informal caregivers. The aim of the present study is to examine these local policies from a cross-border perspective in the Euregion Meuse-Rhine (EMR).

Methods: We conducted 32 group interviews, one per community, including 33 Belgian, 52 Dutch and 27 German representatives. We mainly interviewed policymakers, complemented by representatives of senior groups, care homes or dementia organisations, about existing policies and activities with respect to dementia and prevention of depression and the needs of older people and informal caregivers in the community.

Results: The topics dementia and informal care were more salient in policies than late-life depression. At the same time, all communities found the prevention of dementia and the prevention of late-life depression relatively important (both a mean of at least 3 out of 5 or higher). 17 of the 32 communities already had policies or activities related to dementia, versus 2 / 32 communities related to the prevention of late-life depression. Furthermore, communities reported that activities for the target groups were more present than sec policies to support the target groups. Lastly, the interviews increased awareness of these topics among the interviewees.

Conclusions: To cater for the specific needs of older people with mental health problems, prevention and awareness needs to be increased in the EMR, where communities face similar demographic challenges. This study provides insights into what policies and best practices can be enhanced and exchanged to achieve this goal.

P15. Neuronet

P15.1. A framework for regulatory and health technology assessment engagement in neurodegenerative disease research

O’ROURKE Diana, BOUVY Jacoline

NICE, United Kingdom

Background: Regulatory agencies, health technology assessment (HTA) bodies and payers have a fundamental role in enabling access to new treatments. Many Innovative Medicines Initiative (IMI) projects are developing outputs that are relevant to these stakeholders. To maximise the impact of these outputs and ensure that they are usable within a regulatory and HTA context, there is a need for timely and effective engagement. This is particularly important within the field of neurodegenerative disease research where there remains a lack of effective treatments. We aimed to produce a guide to support a portfolio of IMI neurodegenerative disease projects to engage with EU regulators, HTA bodies and payers with respect to their activities and outputs.

Results: We developed a decision tool framework which identifies the main ways of interacting with EU regulators, HTA bodies and payers. The framework maps the key processes and procedures for engaging
with these healthcare system stakeholders at key stages of the medicines development, approval, and reimbursement pathway, and signposts to further information. The tool has been developed to meet the needs identified by the projects in the IMI neurodegenerative disease portfolio, however, it is intended that it will be applicable beyond the scope of this work.

Conclusion: The decision tool framework provides the first version of guidance to support engagement between researchers, regulatory and HTA agencies in the neurodegenerative disease field. It is anticipated that by engaging with these stakeholders at suitable time points, researchers will be better placed for developing outputs and evidence which can be translated into practice, thereby improving access to new treatments for people with neurodegenerative diseases in the future.

This work has received support from the EU/EFPIA/Parkinson’s UK Innovative Medicines Initiative 2 Joint Undertaking (Neuronet grant n°821513).

P15.2. ROADMAP: regulatory and health technology assessment considerations for new Alzheimer's disease drugs

BOUVY Jacoline, O’ROURKE Diana

NICE, United Kingdom

Although there are a growing number of well-reported late stage clinical trial failures in Alzheimer’s disease (AD), the introduction of a disease modifying therapy within the next 5 years may be anticipated. These treatments are likely to target AD in the earlier disease stages, unlike drugs that are currently available that treat symptoms of moderate to severe dementia. It is important to identify what challenges might exist along the pathway of regulatory approval, health technology assessment, and pricing and reimbursement of new AD drugs.

The ROADMAP (real-world outcomes across the AD spectrum – a multimodal data access platform) project established an expert advisory group (EXAG) to explore what challenges were likely to exist. The EXAG discussions identified the following challenges: a lack of consensus on validated outcomes in the earliest AD disease stages, the need for filling gaps between outcomes used across clinical trials and real-world settings, and the role real-world evidence might have in characterising the impact of a possible disease-modifying therapy on caregivers, resource use, and long-term outcomes.

In this talk, the key issues that the EXAG identified, as well as some of the general ROADMAP findings, will be discussed. Two years after the ROADMAP project ended, we will also explore how much progress has been made to solve some of these challenges.

P15.3. AMYPAD: Lessons and reflections from Regulatory and HTA Interactions

FARRAR Gill

GE Healthcare, United Kingdom

AMYPAD, (Amyloid Imaging for the Prevention of Alzheimer’s disease) aims to better understand the incremental value of amyloid PET imaging to improve 1) the accuracy and confidence of routine clinical diagnosis, resulting in better management and care of dementia patients, 2) increase the understanding of the natural history of AD, and 3) refine the selection of subjects into current and future secondary prevention trials.

1) Diagnostic & Patient Management Study (DPMS) should fulfil EMA requirements for understanding the role of amyloid PET in influencing diagnostic thinking. Additionally, the role and value of amyloid PET will be summarised for HTA purposes to influence routine dementia diagnosis in Europe. Interactions with regulatory authorities and HTAs (via Scientific Advice, SA) were integrated in study design to provide meaningful clinical and health economic endpoints. Future HTA input could be from country specific HTAs or via the European Network for Health Technology Assessment (EUnetHTA), enabling scientific and technical cooperation between HTA bodies (National and Regional), to get an alignment of their assessment criteria.

2) Risk Stratification Study investigates the value of amyloid PET as an early and sensitive biomarker to understand individual risk of progression to AD within the pathology continuum. AMYPAD will obtain EMA’s position (via SA) on the role for PET amyloid radiotracers. Advice would inform how data could support the further development of this concept and also potentially guide the adjustment of regulatory goals and future interactions with regulatory authorities.

3) Monitoring Treatment is a major AMYPAD focus to develop/optimize methods to robustly assess changes in amyloid load quantitatively for the purposes of (a) informing decisions regarding subject selection into treatment (b) effectively measuring early amyloid deposition, and (c) accurately monitoring the efficacy of AD treatments. AMYPAD will also investigate the robustness of quantitative methods to supplement visual image interpretation.

P15.4. The Mobilise-D consortium regulatory strategy for qualification of wearable sensors to quantify mobility in drug trials

VICECONTI Marco1, HERNANDEZ PENNA Sabina2, DARTEE Wilhelmus2, MAZZÀ Claudia3, CAULFIELD Brian4, BECKER Clemens5, MAETZLER Walter6, GARCIA-AYMERICH Judith7, DAVICO Giorgio1, ROCHESTER Lynn8
We present two requests for qualification advice, one completed and one on-going. They delineate the qualification strategy for the use of digital mobility outcome’s (DMOs) obtained from wearable sensors, as biomarkers of mobility performance within regulatory drug trials. Our approach is to claim that mobility should be quantified not only in term of patients’ perception (with questionnaires) and capacity (with clinical tests such as six-minute walking distance) but also in terms of mobility performance, recorded in the real world and for a time sufficiently long time to be representative. This is possible only by using wearable sensors, and special analytical algorithms like the one developed by the Mobilise-D consortium. These new algorithms ensure reasonably accurate measurements of digital mobility outcomes such as walking speed even in subject’s who walk very slowly or who have a pathological gait. In our first request for qualification advice to EMA, we proposed to use DMOs as monitoring biomarkers for mobility performance in patients affected by Parkinson’s disease. In the request we detailed the technical and clinical validation plans we intend to conduct in order to demonstrate the validity of such biomarkers. On the basis of feedback from the EMA, which was overall very positive, we recently submitted a second request for qualification advice, this time extending the context of use to include patients affected by chronic obstructive pulmonary disease, multiple sclerosis, and the outcome of hip fracture.

P16. INTERDEM: How assistive technology supported dementia care during COVID-19: European experiences

Despite reported benefits of assistive technology devices for persons with dementia and their carers, there was reluctance of adopting these technologies by family and professional carers. This spring, as a result of COVID-19, measures were taken in many countries to prevent a major infection of vulnerable elderly people, including people with dementia. In practice this meant less face-to-face contact and support. As a result, alternative means of contact were tried, such as the use of assistive technology tools. In this symposium we will share experiences with consequences of diminished social contact and of the use of assistive technology in several European countries and discuss the lessons learned.

FRANCO Manuel
Spain
Abstract not provided

P16.2. Everyday technologies and people with dementia - access, use and adaptation
BARBOSA Ana, MOUNTAIN Gail
University of Bradford, United Kingdom

This presentation is about the ways in which everyday technologies can be adapted and used to promote independence and wellbeing in people with dementia living in the community. Given that one third of those with dementia live alone, we are concerned with how individuals can be enabled and empowered while appreciating the challenges that emerge across the dementia trajectory. We will also look at how technologies can empower individuals in times of Covid-19.

We all use technology every day. These ‘everyday’ technologies include home equipment (e.g. TVs and microwaves) and Wi-Fi connected devices like smartphones and tablets. Use of the Internet to obtain services, such as shopping, is rising and technologies to link home-based equipment with the Internet (e.g. Amazon Echo) are emerging.

This presentation is based in recently completed funded work, which involved a rapid literature review of evidence, supplemented by searches of the Internet and records of the personal experiences of people with dementia.

We located 39 reviews that met our inclusion criteria and have selected key-studies for in-depth examination. Overall, technologies are reported to be effective, useful, and associated with positive outcomes for people with dementia (e.g. increased independence) and for families (e.g. reduced stress). However, the quality of the evidence is mixed, not robust or easily generalisable. The personalisation of devices has emerged as being significant in meeting individuals’ needs and preferences. The scale of most studies is small which can be attributed to the ever-changing nature of such technologies. Identifying the stages of dementia for whom the reported technologies are intended for is problematic as this is not consistently reported. Finally, identifying the specific function of technologies reported within studies also proved to be difficult as technologies can serve different functions (e.g. phones may be used to communicate with others or for leisure purposes).

P16.3. To make best practice visible: Digital provision of practical recommendations for social participation in the context of Covid-19 in German nursing homes
HALEK Margareta1, AUTSCHBACH Dominique2, JAGODA Franziska2, KIWITT Joern2
1Witten/Herdecke University, 2School Of Nursing Science, Herdecke University, Germany
During the COVID-19 pandemic a particularly affected group are elderly, multimorbid people, as they are at high risk of showing severe courses of infection. Protective measures adopted by the German government were aimed at restricting visits by relatives, neighbours in order to minimise the risk of infection. Nursing homes have converted them into general bans on visits and group activities.

In the time of the crisis, there was no evidence or guidelines how to maintain social inclusion for the residents when physical contact is avoided and distance is kept. Each nursing home has found their own way to deal with these challenges. The exchange of these experiences is very valuable for daily care. Digital solutions are a good way to support this exchange and to back information with current research results.

Our goal is to gather knowledge and make it available in such a way that the staff of nursing homes across Germany can access it even in pandemic situations. A webpage is an accepted low-threshold option for this.

The construction of the webpage content has three steps: online survey, literature review and expert consultations. The survey was sent to n=10472 German nursing homes. It consisted of 14 question that mainly focused on experiences of staff finding helpful interventions for social participation for residents within and contact to family members and friends outside the facility. The survey is still ongoing; the results will be presented during the symposium.

The information from the online survey together with expert’s recommendation and results from the literature forms the basis for the recommendations. The user of the home page can rate the recommendations and add their own experiences with the interventions presented. This evaluation will help to build a bigger body of knowledge while accumulating it in one place, that is easily accessible.

P16.4. Consequences of digital exclusion – reflections from Sweden
ROSENBERG Lena, NYGÅRD Louise, JOSEPHSSON Staffan, WALLES MALINOWSKY Camilla
Karolinska Institute, Sweden

The right to participate in society is fundamental and even stated in our laws. The present situation with older adults being isolated due to the Corona virus shows how vulnerable this right is for those people in our society who have no access to interaction through digital technology.

In the current situation, older adults are at risk of total exclusion from social connections, deprived of their right to participation, with extensive negative consequences, especially for those with cognitive impairments. As we now are told to socialize and take part in societal conversations through digital media, it becomes increasingly obvious that those who lack this possibility are left outside, isolated.

New technology is often seen as the solution to challenges in tomorrow’s care, particularly in elderly care. But the wishes and needs of older adults are rarely driving the development of technology in this field. More often, focus is placed on tech-solutions for eHealth or on more spectacular technology. The everyday technology used by the older adults themselves is less often in focus, but today this is the kind of technology that is needed to maintain social contacts with the surrounding society. That is; technology that enables people to be updated and connected to family and friends, and to access culture and activities that bring pleasure.

Now the exclusion becomes painfully explicit and obvious. This wake-up call shows how some people in our society are excluded from the technology that gives us a possibility to enact our citizenship, technology that we so strongly lean on in our communication today. We should listen to the older adults when they ask for Wi-Fi in nursing-homes, and we need to explore possible avenues to support older adults in their use of those everyday technologies that they want and need to use in everyday life.

P16.5. Consequences of social isolation and uptake of communication technologies in Dutch nursing homes
VAN DER ROEST Henriëtte1, PRINS Marleen1, STOLTE Eiske2, STEINMETZ Stephanie3, VAN TILBURG Theo2
1Trimbos Institute, 2Vrije Universiteit Amsterdam, 3University of Amsterdam, Netherlands

Background: To prevent the infection of residents in long-term care facilities (LTCF) with COVID-19, on March 20, 2020 the Dutch Ministry of Health, Welfare and Sports implemented a visitor ban in all LTCF. Creative ways to facilitate social contact and replace physical visits for residents, including communication technology, were introduced rapidly in LTCF.

The study aims to provide insights into the use of communication technology to facilitate social contact between LTCF residents with cognitive impairment and family members during the visitor ban due to COVID-19.

Methods: Cross-sectional data were collected online among family members and care workers in Dutch LTCF between April 30 and May 27, 2020. Sub-samples on cognitive impairment were used for the analyses. This study is part of the project Corona Times (https://www.coronatijden.nl/) and funded by ZonMw.

Results: 1029/1609 participants were family members of residents with cognitive impairment and 326/811 were staff members working in psychogeriatric units. Family mainly had contact via telephone (61.7%)
and video calls (56.2%). 17.5% of family members did not have contact with the resident in the past four weeks. According to almost all care staff, contact was facilitated by phone (92.6%) and video calls (93.6%). 68.4% of family members reported an increase in frequency of one or multiple mood symptoms. The method of contact had no effect on loneliness and some effect on change in the frequency of expression of fear, happiness and apathy (p ≤ .05).

Discussion: Telephone and video calls were the main methods for social contacts for LTCF residents with cognitive impairment during the visitor ban. The results provide some evidence that video calls with residents are to be preferred over telephone contact. However, communication technology has its limits. It was not suitable for a significant proportion of residents with dementia. Therefore, it is incapable of replacing physical visits.

P17. National dementia strategies

P17.1. Introducing Germany’s National Strategy on Dementia

DAHL Nils
Federal Ministry of Health, Bonn, Germany

The presentation intends to introduce Germany’s national strategy on dementia which was developed between 2019 and 2020. Governmental actors of different policy areas and of all administrative levels, as well as over 50 relevant organisations and interest groups were involved in the process of drafting the strategy. Four priority fields of action were identified: 1) building dementia-inclusive communities by strengthening structures that enable the social participation of people with dementia, 2) improving support for persons living with dementia and their family caregivers, 3) improving medical care, nursing care and long-term care for people with dementia, and 4) promoting research, innovation and collaboration to increase our knowledge on the prevention and therapy of dementia.

All involved actors agreed on 27 goals and 162 measures to substantially improve the situation and living conditions of persons with dementia and their families. Therefore, many measures focus on enhancing the quality of everyday life in their communities and the quality of care in various care settings.

The implementation of the strategy will be monitored to ensure sustainable improvements and to allow necessary adaptations to new challenges such as the current COVID-19 pandemic. The strategy’s goals are interlinked with other governmental strategies such as the so-called “Concerted Action on Care” (“Konzertierte Aktion Pflege” or KAP) which was signed in 2019 to improve schooling and working conditions for professional care workers in Germany.

The presentation will thus share the experience of developing a national dementia plan, discuss examples of the strategy’s goals or particular measures, and enhance the exchange of experiences between countries that have already implemented their individual strategy or that plan similar steps in the future.

P17.2. Development of an Irish Dementia Registry including the identification of outcomes and data that matter most

HOPPER Louise, BOWEN Christina
Dublin City University, Dublin, Ireland

Under the National Dementia Strategy, there is a commitment to improve and increase the evidence we have on dementia in Ireland. This data can improve dementia care management and outcomes for people living with the condition. To support this, the National Dementia Office, through the Department of Health, secured Dormant Account funding for a project to develop a model for a national dementia registry that is workable within an Irish context. This is a summary of the key findings from the project which was co-designed with the active and meaningful involvement of a diverse range of stakeholders including people with dementia and their family caregivers, clinicians, and those with expertise in health informatics, information technology and patient registries. Through a series of co-design workshops, key outcome measures emerged and agreement was reached on those that mattered most to people with dementia and those who care for them. These included a focus on the dementia diagnostic process (currently not standardised in Ireland), overall quality of life and wellbeing of the person with dementia and of their primary caregiver, and monitoring the use of antipsychotic and dementia medication. These outcome measures assisted in the development of a minimum dataset, containing three broad categories of data: Personal Characteristics, Diagnostic data, and Treatment and Care. The Irish system currently has fragmented dementia data that is mostly in paper format or in unconnected systems. This makes retrieval currently difficult. Collecting data in a standardised way through a web based registry application, which is modular and extendable to allow for integration with other health systems over time is essential to track meaningfully outcomes that will drive change, provide a foundation for quality enhancement and add value to our health system and most importantly, to people with dementia living in Ireland.

P17.3. Finnish Age Strategy promotes implementation of memory-friendly practices

VILJAMAA Seija1, HAMMAR Teija2
1Ministry of Social Affairs and Health, Helsinki, Finland, 2National Institute for Health and Welfare, Helsinki, Finland
Background: The population of Finland is rapidly ageing. The share of over-65-year-olds will increase from the current 20 percent to 26 percent by 2030. As the population ages, the number of people with memory disorders is also increasing. Approximately 190,000 persons have some form of memory disorder and over 13,000 are diagnosed with a dementing disease yearly.

Ageing Policy: The Finnish ageing policy promotes older people’s functional capacity, independent living and active participation. The reform of ageing policy and service structures aims to enable older people to continue living at home, even until the end of their lives. The focus of the Government Programme is promoting health and wellbeing, and the memory disorders are recognized as well as other chronic diseases.

The impact targets of the national Age Strategy for 2030:
- Functional capacity of working age people is improved and working careers are extended.
- Older people maintain their functional capacity longer.
- Voluntary work has an established role in society.
- Digitalization and new technologies have improved wellbeing.
- Service system is non-discriminating, coordinated and cost-effective.
- Housing and living environments are age-friendly.

Towards a Memory-Friendly Finland: The national Memory Programme (2012-2020) aims to support people with memory-related diseases to live their lives as active members of the society according to their own capacity, abilities and resources. It includes four main areas:
- Promoting brain health
- Fostering open attitude towards brain health, treatment of dementing diseases and rehabilitation
- Ensuring quality of life
- Increasing research and education.

Many actions have become part of practices and activities in the life of person’s with dementia. The implementation, including new practices like Finger model, continues in social and healthcare reform and the Age Strategy. Specific care guidelines, the Elderly Care Act and the Quality Recommendations for older people services also support the quality of life of people with dementia.

P17.4. Dementia as public health priority - current trends and best practice Austria
RAPPOLD Elisabeth, PFABIGAN Doris
Gesundheit Österreich GmbH (Austrian Public Health Institute), Wien, Austria

In 2012, the WHO and Alzheimer's Disease International called on Member States' governments to recognize dementia as a focus of health policy. The Austrian government included the development of a dementia strategy in its government program 2013-2018. As a result, the Austrian dementia strategy "Living well with dementia" has been developed in a participatory process.

In this presentation will focus on three results on national level:
- Orientation guide for hospitals: For people with dementia staying in a hospital is a difficult and frightening situation. They can be destabilized by a change of location, such as admission to a hospital. The orientation guide shows measures that enable hospitalization for patients with dementia as free of friction as possible.
- Orientation guide for nursing homes: People with dementia represent the largest group of nursing home residents. In order to ensure a good life with dementia there, structures, processes, processes and environmental factors have to be adapted to the needs of people with dementia. The aim of this orientation guide is to support and accompany people with dementia to maintain quality of life, skills and abilities and self-determination despite impairments.
- Both orientation guides were developed on the basis of literature and experts. For the systematic presentation of the recommendations, the SPACE system developed in England was used. Their aspects are: »Staff »Partnership »Assessment »Care »Environment. We expanded the criteria by “Dementia Governance”.

Ornament guide for media: The current image of people with dementia, in the public perception mainly focuses on the advanced stages of the disease or life with high care needs in nursing home. This should be brought into the right light. The guide includes do’s and don’ts both for written reporting and image reporting. Regardless of the type of reporting, it is important to act in an appreciative and strength-oriented manner.

P17.5. Building the dementia pathway
ROBINSON Ella
Alzheimer's Society UK, London, United Kingdom

At Alzheimer's Society, we campaign for better care, support and system reform, knowing from people affected by dementia the number of issues they face in their fight against the disease. This includes
hurdles at various points of the dementia pathway. From diagnosis to death, people are navigating a
disjointed system that fundamentally doesn’t work as well for them as it does for people with other
conditions. People with dementia and their families are left to fight for the care to which they are entitled,
whether it meets their needs or not.

While research continues to strive for a cure in the future, treatments and models of care to support people
in the shorter term, this does not negate the need to take action and focus on what needs to be done
now; stopping people falling through the gaps in the current system and improving quality of life.

Our report forms the first output of a long-term project we are undertaking on the dementia pathway. It
uses people’s experiences to identify the gaps in what care people are receiving, benchmarked against
current national policy.

We take the five stages of NHS England’s Well Pathway for Dementia; Preventing Well, Diagnosing Well,
Supporting Well, Living Well and Dying Well, and explore in detail what NICE and the government say
people should be receiving at each stage, and therefore the care and support they say will enable people
to live well with the condition. We benchmark this against the experiences of people affected by dementia.

We have brought to light the particular challenges people face in accessing effective care and support,
from diagnosis to death. Each gap identified within the pathway is as important as the next, as each type
of support can impact, both positively and negatively, the rest of a person’s pathway.

P18. Acute and hospital care

P18.1. The Village Landais: a new innovating and caring structure in south-west of France

GALIBERT Vincent
GIP Village Landais Alzheimer, Dax, France

Few years ago, the Landes Department, decided to launch a new way to care for people with Alzheimer’s
diseases. First of its kind in France, second in Europe, the Village Landais, in Dax, will be a new facility
where people suffering for Alzheimer’s diseases will go on living « like at home ».

The Village Landais will be a white-coat free zone with a non-drug approach within a secure environment
in small housing units. It will house 120 residents, including 10 under-60s, supported by 120 staff and 120
volunteers. 12 places for people suffering from Alzheimer will be available in a day-care unit. The role
given to families will be paramount, from setting the private rooms with their dear one’s own pieces of
furniture, to the monitoring of the residents welfare.

The architecture is set up to be like a real village from the Landes’ countryside so that the residents will
live in an environment they identify with and feel safe in. The Bastide, central square of the structure, will
contain a restaurant, an auditorium, a multimedia library, a hairdresser salon, a health center and a small
food store. All of these equipments will be accessible for inhabitants of Dax city. Residents will be living
in a wide natural setting as they can freely wander in the 5 hectares park.

Residents will live in 7 or 8 people houses. Each neighborhood, of 4 houses each, will have its own
characteristics inspired by different areas from the Landes Departement.

The Village will also be a resource center for medical and therapeutic research. Several evaluation studies
will be conducted to measure the exemplary and effective nature of this innovative structure. All the
medical, medico-social actors and careres as well will be able to find additional support or new models of
care.

P18.2. Before the end of life in patients with Alzheimer’s disease

IOANCIO Ioana, SPIRU Luiza
Spitalul Universitar de Urgenta "ELIAS", Clinica Universitara de Geriatrie Gerontologie, Psihogeriatrie

Alzheimer's disease is considered a neurocognitive disease with a slow evolution, experiencing a plateau
in development when patients have been diagnosed early, have followed a closely monitored treatment
and have been constantly clinically reevaluated. Support, both medical and from the family of the patient,
are the key for a prolonged evolution of this irreversible illness.

Aims: Our study’s primary objective was the gerontopsychiatric evaluation of the final period of life of
patients with Alzheimer’s disease, within the acute and hospital care cadre.

Methods: Our study was fulfilled in the Memory Clinic, Elias University Emergency Hospital, Bucharest,
Romania, in the years 2017-2020. 117 patients diagnosed with Alzheimer's disease, 77% women and
23% men, aged 72 years and over were enrolled in the study using international diagnostic criteria. We
evaluated the patients as well as yearly and the next three years follow-up. Subject evaluation was
performed by a complex neuropsychological battery: Standardized Geriatric Evaluation.

Results: In the final months of life, patients admitted to our clinic have described three kinds of evolution.
In one group, patients have resignedly looked towards the end, expressing requests to return "home", in
the company of their closest relative and with their favourite food. Another group has presented episodes
de delirium, with psychomotor agitation and reversal of their sleep-alert schedule. The majority of patients
met their end through comorbidities: sepsis, strokes, cancer or cardiovascular pathologies.
Conclusions: Patients with Alzheimer's disease that are correctly treated and monitored meet their end through different pathologies, the most frequent being intercurrent infections, respectively sepsis. In the brief moments of lucidity, they evoke the image of their home.

**P18.3. Withdrawn**

**P18.4. Dementia Nurse Consultants: building bridges between Scottish Government, the NHS and the charitable sector**

SKINNER Helen¹, MCCRIMMON Tilda²
Alzheimer Scotland, United Kingdom

**Background:** Since 2011, Alzheimer Scotland, Scottish Government, and every NHS Health Board in Scotland have been collaborating to fund a Nurse Consultant (ASDNC) post focused on acute hospital care in every region in Scotland.

**Aim:** Through individual and collective responsibility, the key aim of the Nurse Consultants was to deliver the commitments in Scotland’s National Dementia Strategies which called for action to improve the experience of people with dementia, their families and carers in acute care and specialist dementia settings.

**Objectives:**
- To implement the 10 Dementia Care Actions in Hospital;
- To shift the paradigm of care for people with dementia in hospital settings;
- To develop actions to reduce delayed discharges, avoidable admissions and inappropriately long stays in hospital and demonstrate impact;
- To influence and advise on national dementia policies and strategies.

**Participants/methods:** This presentation draws on the key reports, achievements and impact areas of the Alzheimer Scotland Dementia Nurse Consultant group from 2015-2020, including during the COVID-19 pandemic, and sets out a dynamic action plan for future improvements.

**Key Findings:** The presentation highlights:
- The value of a co-ordinated national high-level nurse consultant group;
- The need for a multi-pronged approach and the value of working with the 1000 Dementia Champions in Scotland;
- The improvements to the experience of care for each of the 10 dementia care actions for hospital across the domains of Nurse Consultants: expert practice, professional leadership and consultancy, education training and development, and practice and service development;
- The value of a specific ASDNC focus on NHS24 emergency and crisis care.

**Conclusion:** Whilst there is clear evidence of improvement associated with the role of the ASDNC there remain significant system challenges to reducing delayed discharges, avoidable admissions and inappropriately long stays in hospital.

**P18.5. Nurses’ experiences of delivering acute orthopaedic care to patients with dementia**

JENSEN Anders Møller¹, HOUNSGAARD Lise², WILSON Rhonda³, PEDERSEN Birthe², OLSEN Rolf⁴
1VIA University College, Holstebro, Denmark, 2University of Southern Denmark, Odense, Denmark, 3The University of Newcastle, Ourimbah, Australia, ⁴-, Odense, Denmark

**Background and aim:** Nurses who care for acute patients with dementia in a hospital setting report a variety of challenges in regard to meeting the complex needs of their patients, but little attention have been given to care in the orthopaedic wards. This study investigates nurses’ experiences of caring for people with dementia, in an acute orthopaedic hospital ward setting.

**Methods:** This qualitative study employs hermeneutic phenomenological research methods. Eight Danish nurses were interviewed in an orthopaedic ward about their experiences in caring for orthopaedic patients with dementia. Nurses with various levels of expertise were selected for interview so that a full range of nursing experiences could inform the research study. The interviews followed an intense participant observation period at the ward.

**Results:** The results of the study revealed two major themes: "Nurse communication and patient information" and "Care compromise", with three and four sub-themes, respectively. These findings are used to illustrate how, and why, nurses’ experiences of caring for patients with dementia contribute a discontentment and negative preconceived perception by some nurses towards their acute care of patients with dementia. The results are discussed in the context of Interactional Nursing Practice theory and describe the challenges experienced by acute care orthopaedic nurses who care for patients with dementia.

**Conclusion:** Orthopaedic nurses find it challenging and professionally difficult to provide person-centred care for patients with dementia during an acute orthopaedic hospital admission. Orthopaedic nurses
should work to adopt a positive attitude, and person-centred approach, towards dementia care. It is also recommended that the electronic patient record should be supplemented by oral dissemination to some extent, as information, plans of action and knowledge about the care situation for patients with dementia tends to drown in chronological data presentation.

**P19. Dementia research and AI: ethical, legal and social implications**

**P19.1. Responsible AI - Implications for Brain Research**

*STAHL Bernd*

De Montfort University

Artificial intelligence (AI) offers numerous advantages to brain research that would be difficult or impossible to realise. AI may help better understand brain diseases, which can lead to better treatments. AI can provide clinical support and may pave the way to personalised treatment. These benefits, however, need to be balanced with possible ethical and social concerns.

In this presentation I will draw on work undertaken in the context of the EU project SHERPA, which explores ethical and human rights aspects of AI and big data analytics. Drawing on the findings of this project, I will discuss different concepts of AI and ethical issues that are linked to these, in particular how they are linked to brain research.

Following a brief overview of the current discussion of ways of dealing with the ethics of AI, I will introduce the metaphor of an ecosystem that is frequently applied to AI. I will discuss which implications this metaphor has for the ethics of AI and which conclusions can be drawn from this for balancing risks and costs of AI in brain research.

**P19.2. Legal considerations for data protection in AI-driven health research**

*CEPIC Michael*

University of Vienna/Department of Innovation and Digitalisation in Law

As pointed out by the session’s title, Dementia research and AI have ethical, legal and social implications. Both research and AI, separately and when they are combined, rely heavily on the use of data. The information of foremost interest for health research lies in personal data, making the European General Data Protection Regulation applicable. The tension between health research and data protection must be balanced by contemplating conflicting but also common interests. The legal considerations vary from the quality of the data (pseudonymisation/anonymisation) and the subjects involved (frequently patients), to the security of the data processing. When a certain processing of personal data involves the use of AI, the data protection regime asks for more drastic measures to guarantee the safeguarding of data subject’s rights and freedoms and legitimate interests.

An analysis of legal considerations for data protection in AI-driven health research also requires to discuss the relationship between Articles 9 and 22 of the GDPR, as the processing of genetic data or data concerning health is considered a special category of personal data, mandating a higher protection. Furthermore, it should be developed, how the term profiling is coined and what the use of predictive software entails legally.

On top of these issues and especially in light of the developmental stages of research projects, the data protection by design principle should be discussed.

**P19.3. Ethical challenges associated with the digital detection of dementia**

*MILNE Richard, COSTA Alessia*

Wellcome Genome Campus

There is growing interest in the development of data-driven and AI technologies for the detection of cognitive decline and early diagnosis of dementia. Such technologies involve new collaborations and encounters between clinicians, clinical researchers and scientists and companies working on technology and AI. This paper reviews ethical questions raised by AI and data-driven technologies for the detection of cognitive decline, situating these at the intersection of discussions of dementia research ethics, data ethics and the ethics of AI and algorithms. The paper draws on findings from an ongoing research study with academic and clinical researchers and technology companies to identify emerging ethical issues associated with digital tools for the early diagnosis of dementia.

This session is organised by the H2020 Virtual Brain Cloud project

**P20. BBDiag: Blood-based diagnosis of Alzheimer's disease**


*PAN Genhua*
The identification of early stages of Alzheimer’s disease (AD) before significant brain damage occurs is a key requirement for the development of disease-modifying drugs and preventive strategies, as treatment on established disease is unlikely to prevent the progression of the disease. The existing established methods for diagnosing AD are either invasive, with limited accessibility, and/or expensive, and there is a strong recent research interest toward blood biomarker based diagnostics. The BBDiag – an EU H2020-MSCA Innovative Training Network (http://bbdiag-itn-ett.eu/) was timely funded by the European Commission in 2017 for the training of a new generation of young researchers through a multidisciplinary and multisectoral research platform. The scope of the BBDiag project is to explore easily accessible, minimally invasive and inexpensive blood-based biomarkers, biosensing techniques including graphene-based and digital ELISA-based technology, novel information technology solutions to facilitate the discovery of blood biomarkers, and development and possible commercialisation of point of care (PoC) diagnostic devices to be used at patients’ home or residency home. In this symposium, the young researchers will illustrate and discuss the main concepts and findings of the BBDiag project to frame and validate blood biomarkers in the diagnosis of AD.


P20.2. Novel biomarkers of Alzheimer’s disease

TZARA Ourania6-9, EKE Chima3-6, BLUMA Marina1-5, BOLELLI Aronne2-9, MORADI-BACHILLER Soraya2-9, SAKR Fatemah4-5-9, VAN BULCK Michiel2-8, ALBANI Diego2, BRAUER Anja8, CLAUDIO Babiloni1, HENRIKSEN Kim6, IFEACHOR Emmanuel3, PEREZ-CASTILLO Ana7, TEIPEL Stefan4-6

1Department of Pharmacology and Physiology "Vittorio Ersipamer", Sapienza University of Rome, Rome, Italy, 2Istituto di Ricerche Farmacologiche Mario Negri, Milan, Italy, 3Signal Processing and Multimedia Communication Lab, School of Engineering, Computing and Mathematics, University of Plymouth, United Kingdom, 4Clinical dementia research Department, University Medicine Rostock, Rostock, Germany, 5German Center for Neurodegenerative Diseases (DZNE), Rostock, Germany, 6Nordic Bioscience, Biomarkers & Research, Herlev, Denmark, 7Anatomy Research group, School of Medicine and Health Sciences, Carl von Ossietzky University, Oldenburg, Germany, 8Centro de Investigación Biomédica en Red de Enfermedades Neurodegenerativas, Madrid, Spain, 9BBDiag early stage researcher

We developed several approaches in preclinical and clinical studies to measure blood biomarkers that may reflect early pathological changes in AD and provide diagnostic and monitoring biomarkers and new endpoints for therapeutic interventions. Highly specific ELISAs were adapted for the serological detection of proteolytic fragments of brain-derived proteins related to AD neuropathology2-3. Novel paradigms measured the balance of circulating free nuclear DNA and circulating free mitochondrial DNA as well as exosomes. Other multifactorial approaches derived proteomics and lipidomics-based biomarkers to probe metabolic pathways driving AD progression. Those blood biomarkers were validated in relation to established translational biomarkers of brain amyloidosis and neurodegeneration in AD derived by cerebrospinal fluid (CSF) Aβ-42 and p-tau levels and neuroimaging measures of cerebral atrophy. The association among blood biomarkers and established translational biomarkers was modelled by linear and nonlinear statistical procedures including machine learning. Among them, a panel of blood biomarkers of the BBDiag studies was associated with cerebrospinal fluid (CSF) Aβ-42 status, especially in combination with the APOE4 genetic risk of the sporadic AD in patients4-5. Furthermore, we proposed a novel sensitive approach for amyloid burden quantification in-vivo based on amyloid PET scans and explored its clinical validity particularly in preclinical or prodromal populations6,7. The approach was able to spot communities/subgroups vulnerable to clinical progression and hence could act as a reference for validating novel biomarkers in the early phase of AD. Concerning preclinical studies8-9, a longitudinal MRI study of double and triple transgenic mouse models of AD was conducted to elucidate how different genetic variations contribute to the brain structural phenotype. The results of this investigation have pointed out different neuroanatomical trajectories in models with double and triple mutations in APP, PS1/PS2, and Tau9.
Novel label-free graphene biosensors have been developed for the detection of candidate blood AD biomarkers\textsuperscript{10,11}. These biosensors provide ultrasensitive and reliable detection of extremely low diagnostic concentrations for AD patients and can be adapted for the detection of a panel of AD biomarkers. We also developed a novel microdroplet array based digital ELISA for the detection of single molecules in the aM - zM range. A microfluidic system prototype is proposed to multiplex this kind of assay and generate ultra-sensitive and fully automated PoC devices able to detect several AD biomarkers at the same time. For the analysis and interpretation of the clinically relevant information and blood biomarker data in AD patients, we developed two mobile applications (apps)\textsuperscript{12}. One aims at supporting medical professionals and the other for use at PoC. Principles of user centred design and participatory research were employed in the development and testing of those procedures. The acceptance of the applications by the intended user groups was ascertained with semi-structured interviews. For commercialization, a new business model was designed\textsuperscript{13} to describe how a business creates and delivers value to users, and converts payments received into profits. Four key dimensions were included: value proposition, value beneficiary, value chain, and value capture. Current findings suggest that all stakeholders can benefit from the PoC device for early stage AD diagnosis, so commercialization would have relatively high chance to reach the planned targets.


\textsuperscript{11}Sethi, J., Suhail, A., Safarzadeh, M. et al. A novel functionalization technique for femto-molar label-free detection with reduced graphene oxide screen-printed electrodes. (To be submitted)

\textsuperscript{12}J. Janson, C. Babiloni, S. Teipel, S. Köhler, R. Lizio, D. Görß ; Stakeholder view on assistive mobile applications for people with mild cognitive impairment due to Alzheimer’s disease; Technology and Dementia Preconference Poster #45823; AAIC 2020 (Accepted)


This session is sponsored by BBDiag.
understanding how best to improve the journey of dementia for the person diagnosed and the family caring for them. Our advocates identified the need for a peer-to-peer support for carers with regard to good nutrition for a loved one living with a diagnosis of dementia. Good nutrition is essential for the health and wellbeing of the person being cared for. It can be challenging for people with dementia to get the correct nutrition through food particularly as the illness can affect each person differently.

As our advocates had previously been involved in the production of the successful booklet ‘Eating Well with dementia, practical tips for family carers’ they determined the need for complimentary videos featuring carers. Their aim was to share their experiences of caring for a loved one to offer real life insight into the main topics detailed in the booklet.

Our advocates will present video clips which include their real-life experience and evidence based professional tips and information. The videos focus on aspects of nutrition from shopping for ingredients, preparing meals, dysphagia and the social impact of eating together. For example: https://www.youtube.com/watch?v=dDk3LN3yPmc

Our presentation will show the unique type of empathy and reassurance that peer-to-peer videos can offer family carers who find themselves in the upsetting situation of seeing a loved one struggle with eating and drinking or weight fluctuation.

The booklet ‘Eating Well with Dementia, practical tips for Family Carers,’ was funded through an educational grant by Nutricia. The organisation also collaborated with the Alzheimer Society of Ireland to support the Dementia Carers Campaign Network to create the complimentary videos.

P21.2. On the relationship between hearing and memory: evidence from 51 countries
CUTLER Stephen1, ILINCA Corina2
1University of Vermont, Burlington, United States, 2University of Bucharest, Bucharest, Romania

An increasing amount of research has examined the relationship between some aspect of hearing and some aspect of memory. This body of evidence has consistently shown that hearing and memory are related to one another. In fact, enough evidence exists that some have concluded that hearing loss may be a precursor to dementia in general and to Alzheimer’s disease in particular. Yet, all such investigations are country specific: although the findings tend to be consistent, the results are based on studies conducted primarily in one country. The present study extends prior findings by looking at the relationship between hearing acuity and cognitive difficulties in 51 nations. To do so, we draw upon data from the Integrated Public Use Micro-Sample International series (IPUMS-I) available at the Institute for Social Research and Data Innovation at the University of Minnesota. Included in these samples of census data from individual countries is a series of questions assessing whether persons in the household have functional limitations. Among these functional limitations are hearing and cognitive limitations. For each of the countries where data are available, we look at the bivariate relationships between hearing and cognitive problems using correlation coefficients (Rs) and at the multivariate relationships using linear regression techniques (Betats), controlling for age, sex, marital status, and education. For the full set of 51 countries, the R between hearing problems and cognitive problems is 0.334 (p<.001) and the multivariate Beta is 0.316 (p<.001). Among our principal conclusions are that the relationship between hearing and memory appears to be universal; that the results of our study support efforts to examine further the linkages between hearing and cognition; and that practitioners need to carefully assess their client’s hearing abilities before they expect them to be able to remember any information practitioners wish to provide.

P21.3. Anemia – A risk factor of Alzheimer’s disease in elderly people
DOSCAN Ana Maria, IOANCIO Ioana, SPIRU Luiza, NICULESCU Mihaela Cosmina
1Elias’ Emergency University Hospital – Clinical Department of Geriatrics, Gerontology and Old Age Psychiatry, Bucharest, Romania

Introduction: Nowadays, researchers focus on discovering new risk factors involved in the development of cognitive impairment. And anemia seems to be involved in the deterioration of cognitive function. In elderly patients, anemia can be caused, most frequently, by: oncologic diseases, gastro-intestinal pathology, renal impairment, malabsorption/malnutrition, or the physiological process of ageing.

Aims: Our study’s primary objective was to demonstrate that in patients with cognitive impairment associated to anemia, this association has worsened their neurocognitive status.

Methods: We designed a retrospective observational research using patients from the Memory Clinic within” Elias’ Emergency Hospital in Bucharest, Romania. All the patients were evaluated at admission with Standardized Geriatric Evaluation and hematological evaluation.

Results: During 2015 in our Clinic 466 patients with dementia were admitted, thereof 67 also had associated Anemia. (14.37% patients with dementia and anemia). Out of the Dementia lot, the distribution was as follows: 44.77% patients with Alzheimer disease (n=30), 52, 23% patients with Mixt Dementia (n=35), 2,98% patients with Vascular Dementia (n=2).

In the Anemia group, the distribution was as follows: Macrocytic 13.43%, Microcytic Anemia 31.34%, Deficiency Anemia 55.22%.
Conclusions: The extensive monitoring of patients with Alzheimer’s disease and anemia showed an improvement in the cognitive status after the diagnosis and personalized treatment of the cause (anemia), and also of the effects. The most common cause of anemia in elderly people consists of nutrients multiple deficits, so we decided to follow-up the patients at risk, both by the cognitive impairment as well as other comorbidities, for a longer period of time.

**P21.4. ALFA: a national pilot cohort to improve prevention**

FRASCA Guillaume

France Alzheimer and related diseases, Paris, France

Prevention is a key element to fight Alzheimer’s disease. It is estimated that about a third of all cases could be prevented through appropriate measures to mitigate potentially modifiable risk factors. It is also known that relatives of people living with dementia can be of higher risk due to shared factors (same genetic background, similar environment and behaviors, etc.). Another major issue is to take care of the caregivers’ health.

To address the importance of several genetic and environmental risk factors for dementia, France Alzheimer has decided to launch a unique research program called ALFA (for ALzheimer’s FAmilies).

A national cohort will be constituted gathering three groups: (i) people living with dementia, (ii) their caregivers and (iii) their relatives (parents, siblings, children).

These three groups will be followed by several clinical visits measuring their cognition for patients with dementia and their relatives, their overall, their overall health and medical history, whereas the caregivers will be asked about their burden and the care provided. A biobank of blood samples will be collected from people living with dementia and their relatives. Each participant will also be asked to answer several online questionnaires to assess their nutrition, physical activities and general knowledge about the disease.

Finally, the cohort will form an online community connected through an Internet forum helping them to share tips and worries about the situation.

A pilot program will be set up by three memory centers, in Toulouse, Montpellier and Rouen. It is planned to follow 150 clusters (composed of one people living with dementia, one caregivers and one or several relatives) during 24 months. Its goal is to assess the feasibility of such a cohort.

**P21.5. Risk of falling for people living with dementia at home: the Bavarian Dementia Survey (BayDem)**

NAGEL Andreas1, KOLOMINSKY-RABAS Peter1, GRÄssel Elmar2

1Interdisciplinary Center for Health Technology Assessment (HTA) and Public Health (IZPH), Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany. 2Center for Health Services Research in Medicine, Department of Psychiatry and Psychotherapy, University Hospital Erlangen, Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany

Background: People living with dementia (PLWD) are at high risk of falling. Loss of mobility and independence as well as increased mortality are often consequences of falls in these people. The objective of this study was to identify factors that influence the risk of falling for PLWD living at home.

Method: The Bavarian Dementia Survey (BayDem) is a multicenter longitudinal study that was carried out at three locations (Dachau, Erlangen, Kronach) in Bavaria. Participants were PWLD (according to ICD-10) who lived in a home environment and their caring relatives. Data were collected in standardized interviews in cooperation with local actors. The fall event was recorded with the question “Have you fallen in the past 6 months so that medical treatment was necessary?”.

Results: Data of 275 PLWD was analyzed at baseline. The fallen PLWD (n = 90) were older (82.56 vs. 80.14 years) compared to the non-fallen (n = 185), had a higher intake of medications (7.42 vs. 5.89), had a lower BMI (24.50 vs. 26.02) and a higher Mini-Mental-Status-Test score (18.01 vs. 16.94).

Conclusion: Potential risk factors for falls from PLWD were identified. These risk factors can potentially be positively changed through targeted interventions and therapies. So far, guidelines for fall prevention only exist for the institutional context. Therefore, further analyzes are required to be able to derive effective fall prevention measures based on these results, also for PWLD living at home. These should be aimed at both professional and informal caregivers to reduce the risk of falling for PLWD in as many ways as possible.

Funding: BayDem was funded by the Bavarian Ministry of Health and Care (funding code: G42b-G8092.9-2014/10-7).

**P22. Involving people with dementia**

**P22.1. The Scottish Brain Health Register: an evidence-based approach to integrating research into clinical services**

KILLIN Lewis1, PEARSON Jim2, RITCHIE Craig3, GREGORY Sarah1, WINKLER Krista4, DOLAN Clare1, HUNTER Matthew1, JOBSE Hannah1, SPARKS Sarah1, INGRAM Catriona6, GARDINER Rosemary6
Recruitment is a long-standing challenge in dementia research (Fargo et al., 2016) and affects the rate at which scientists discover new evidence. Research poised to impact the lives of those living with dementia (PwD; e.g., developing new treatment or evaluating post-diagnostic care) requires that these same people are given the opportunity to take part in studies. Therefore, the presence of research opportunities in clinical services is critical; this has been the ambition of the Scottish Brain Health Register (SBHR).

We adopted the Theory Of Change methodology (TOC; Connell et al., 1995) to evaluate how to establish SBHR into a memory service in Edinburgh, Scotland. Following ToC guidelines, we adopted a mixed-methods approach to create a situation analysis, intervention plan and impact assessment. This included a review of referral rates of PwD to SBHR and two sets of semi-structured interviews with clinic staff.

Data prior to our intervention demonstrated that although its membership was evenly split between PwD and healthy controls, only 17.3% of PwD seen in the clinic registered to SBHR, and most who were not were labelled as “not suitable [for research]”. Members of the clinical team were happy to discuss research with PwD, although requested more information about what research involves. In response we employed regular clinician-researcher meetings and one-to-one staff training sessions. In March 2020 the rate of PwD referral onto SBHR remained at pre-intervention levels. Post intervention, clinic staff continued to lack confidence to communicate benefits of research participation to patients.

The cases where PwD were not offered the opportunity to take part in research suggests that many assumptions still remain about what participation entails. While it may be possible to establish regular dialogue about research in a clinical setting, it is critical that researchers communicate the exact process and potential benefits of research participation.

**P22.2. Sexual expression in persons living with dementia and impact on person-centred nursing in a care home setting: a phenomenological inquiry**

**RENNIE Karen**
Queen Margaret University, Edinburgh, United Kingdom

**Introduction:** I am a final-year PhD Candidate at Queen Margaret University, exploring sexual expression in persons living with dementia. Research shows that sexual expression provides emotional and physical benefits throughout life and does not diminish with age or loss of capacity (Rennie et al 2017). However, sexual expression is often overlooked and is considered the most difficult ‘symptom’ of the behavioural and psychological symptoms of dementia (BPSD) model to manage by nurses (Tucker 2010). Other literature also demonstrates that the idea of sensuousness might be useful to this research.

**Aims/Objectives:** This study aimed to explore relationship between sensuousness and sexual expression.

**Methodology:** Drawing on an existential phenomenology and person-centred theory with additional participatory research principles, I had conversations with persons living with dementia to explore the nature and meaning of sexual expression; and I observed nurses and had dialogues with them and families at work to find out about their experiences of sexual expression within caring.

**Results:** This study aimed to generate new knowledge on the meaning of sexual expression in persons living with dementia for person-centred practice and theory. Findings will enhance nurses understanding of how to respond to sexual expression in more person-centred ways. Findings are organised around: (1) nurses understanding of sexual expression for persons living with dementia and connection to personhood; (2) facilitating space and privacy for sexual expression; (3) one’s own perspective on sexual expression and intimacy; and (4) the values and needs of persons with dementia (5) sexual expression as sensuousness.

**Conclusions:** Practically, this study generates new principles for how nurses can provide more person-centred care when caring for persons living with dementia. This research challenges the BPSD model and its underpinning ideas and reframes sexual expression within sensuousness.

**P22.3. Innovative methods for involving people with dementia and carers in the policy making process**

**KEOGH Fiona1, ROCHFORD BRENNAN Helen2, O'SHEA Eamon1**

1NUI Galway, Galway, Ireland, 2Alzheimer Society of Ireland, Sligo, Ireland

**Patient and public involvement (PPI) in research is becoming well established. There are fewer examples of PPI in the policy making process, particularly for groups whose ability to participate may be affected by a disability, such as people with dementia. However, the principles of engagement and inclusion in democratic processes are as important for this group as for other citizens. We used three innovative methods to increase the involvement of people with dementia and family carers in the policy making process.

First, a Policy Café was co-developed and involved ten people with dementia who discussed policy developments they wanted to see in relation to diagnosis, post-diagnosis and home care provision. Second, a Carer’s Assembly of 30 caregivers of people with dementia used a citizen’s assembly model to identify the priorities of family carers in relation to services and supports. Third, a Policy Dialogue was
organised in partnership with the Department of Health to discuss the development of a new statutory home care scheme with 24 stakeholders.

The key messages from the Policy Café and the priorities identified by carers were brought to the Policy Dialogue through film, illustration and direct PPI representation at the meeting. This provided a direct access route to inform thinking on the new home care scheme.

We found that involving people with dementia in policy development requires time and creativity to facilitate and maximise their involvement. Co-production is essential to ensure the priorities of people with dementia and carers are identified and expressed. The use of innovative methods and different media, such as film and illustration, contributes to meaningful involvement and accessible outputs for people with dementia. Policy-makers need to hear the direct and authentic voice of people with dementia and carers when making important policy decisions.

P22.4. Using public transport: experiences of people with dementia

BLAKE Cathal
School of Psychology, Dublin City University, Dublin, Ireland

Public transport is important for mobility allowing people to travel longer distances when compared to walking and cycling, which is important for societal participation. Increasingly, social participation is seen as an important contributor to health and wellbeing. However, the increasing proportion of people with cognitive impairments such as dementia, may mean that for this cohort, the use of public transport is compromised. This is an important issue as a person who is not autonomously mobile may have to rely on the support of family, relatives, friends, or social services. A significant body of research concentrates on individuals with physical impairment, with a paucity of research focusing on individuals with cognitive impairments.

Members of the Irish Dementia Working Group raised the issue of public transport for this cohort. The group expressed concerns regarding lack of public transport, fear around independence and in particular their worry about what happens when a person can no longer drive, and decided to research this topic. Utilising Public Patient Involvement (PPI) the group wanted to explore the experiences of people with dementia using public transport across all aspects of the "The Travel Chain".

The overall aim of the research was to capture the experiences of members as they made a variety of journeys on public transport. The specific objectives of the study were to:

- Review the literature on the issue of public transport and access for people with dementia.
- Conduct a qualitative analysis of the experiences people with dementia have when using public transport across the "Travel Chain".
- Collate the findings from this analysis and subsequent recommendations.

Detailed thematic analysis of the interview transcripts and participants’ diaries and field notes uncovered both dementia specific and environmental factors. Positive experiences facilitated public transport use, while negative experiences acted as barriers for the participants.

P22.5. Experiences with the first supported self-help group in Luxembourg

SCHMITT Hildegard
Association Luxembourg Alzheime, Luxembourg, Luxembourg

Background: In 2017 the first supported self-help group for people in an early stage of dementia was established in Luxembourg. The prevalence rate of dementia does not differ from that in other Western European Countries. Nevertheless, Luxembourg’s situation is special: being an immigration country with 48% of the population having a foreign nationality, resulting in a high variety of cultural backgrounds.

Questions: Besides the overall aim to maintain and improve the participants quality of life, the paradigm shift that emerged in recent years, should be put into practice: not professional caregivers but people with dementia themselves are the experts of their own life. How to ensure that they can continue to live in a self-determined way as long as possible? How can we get society to understand that after the diagnosis of dementia an autonomous life is possible for years/decades?

Method and Outcome: In 2018 with an experience of 1.5 years, the group concept was evaluated by the means of qualitative interviews with the participants. The following insights we have gained have already been (partly) implemented: in addition to the monthly discussion-meetings the participants wanted to have more common activities (to visit former group members, museums). Moreover, they asked for support to enhance the participation in their community life outside the group. Having in mind the needs and resources of the group members as well as the readiness of the public, these aims can only be reached step by step. One first step on our way towards a wider audience was to seek the exchange with other professional caregivers from our services.

Perspective: In autumn 2020 we will be able to share new experiences of how the corona crisis has affected group work and what possible consequences will arise in the longer term.
P23. Public-private partnerships in the post-COVID era

OWENS Andrew1, HOFMANN-APITIUS Martin2, MAETZLER Walter3, PREHN Jochen4, RITCHIE Craig5, ROCHESTER Lynn6, VISSER Pieter Jelle7

1King's College London, United Kingdom, 2Fraunhofer Institute for Algorithms and Scientific Computing (SCAI), Germany, 3University Hospital Schleswig-Holstein, Campus Kiel, Germany, 4Centre for Systems Medicine, Ireland, 5University of Edinburgh, United Kingdom, 6Newcastle University, United Kingdom, 7Maastricht University, Netherlands

The Neuronet Coordination and Support action brings together 18 neurodegeneration projects funded by the IMI. In this live roundtable session, Neuronet project leader Lennert Steukers will moderate a discussion on how COVID-19 has affected large public-private partnership projects, involving IMI project leaders who are experts on mobility disorders, big data, digital biomarkers, stratified medicine and dementia prevention. Specific topics to be addressed include the research challenges caused by the ongoing pandemic, and how to ensure that neurodegenerative disease research remains a priority in the post-COVID period.

This session is organised by Neuronet.

P24. INTERDEM: Impact of COVID-19 on dementia services and staff: inspiration for novel research

The COVID-19 pandemic imposed a wide range of limitations across services dealing with care of people with dementia and their caregivers. Most of the community services have been closed and long term care settings face limitations in access. People with dementia and staff, in different settings, have had to develop new ways to ensure care while preserving safety of both clients and staff.

New approaches have been undertaken to ensure the continuity of care and to support people with dementia and caregivers. Also staff working in care setting had to face new challenges linked to isolation and restrictions, mainly of contacts and visits.

In this symposium ongoing challenges faced by services and staff will be described. The consequences of anti-epidemic measures will be illustrated using case studies and the challenges of staff working in different settings will be described. The impact of isolation and safety measures on patients with dementia, their family caregivers and staff will be explored with the aim to gather a better understanding and to suggest new research perspectives, learning from the pandemic experience.

We will provide insight into the UK experience of the staff working in an acute mental health setting and ways to support staff distress related to care in time of COVID-19; a Czech Republic experience of caring for people with dementia and vulnerable groups; a Spanish approach focusing mainly on using telepsychogeriatric care and an Italian experience about reorganizing activities for people with dementia in residential setting.

The experiences developed during this emergency period offer the opportunity to rethink ways of proving care and stimulate new issues to be considered by the research agenda at national and European level.

P24.1. Supporting inpatient mental health care in dementia during COVID-19

WOLVERSON Emma
The University of Hull, United Kingdom

The admission of people with dementia to specialist inpatient mental health settings is only considered when the person is experiencing high levels of distress to such a degree that other settings are unable to meet the person’s needs or to keep the person or others safe.

Staff working in inpatient dementia settings face a number of challenges, balancing organisational pressures; mental health legislation; and patient care. There is very little research exploring inpatient staff experiences, although dementia care research indicates that supporting people with dementia in distress understandably has an impact of the health and wellbeing of staff. The worry is, of course, that distressed and burnt out staff respond in more reactive and less thoughtful ways and that this may lead to the increased use of restrictive interventions and the unnecessary prescribing of antipsychotic medication.

In the midst of COVID-19, creating a positive workplace and looking after the mental health of inpatient dementia care staff has never been more crucial. In this presentation, I will reflect on my experience as a clinical psychologist of supporting staff at one inpatient setting during the pandemic, considering the impact of the staff members’ fear; anxieties; and feelings of vulnerability on patient care. I will also consider the wider impact of COVID-19 on the inpatient dementia sector and the challenges that it raises.

It is important to recognise that inpatient dementia care poses unique challenges and that this is currently an under-researched area. Research is needed to understand how we can best support staff, both to ensure that they give their best and that the human rights of people with dementia are upheld at a time when they may be most vulnerable.
The World Health Organization (WHO) has raised its global risk assessment of the coronavirus disease (COVID-19) to the highest level. In the case of Spain hasn’t been different and COVID-19 outbreak has become a great challenge to the Spanish Health System. People with dementia (PwD) have been a group especially vulnerable to COVID-19 disease and relevant measures were taken for protecting them from the risk of being infected from the beginning. Lockdown most of the nursing homes, movements restrictions specially for the older people, limitation of the accessibility to the primary care centers changed the regular living of people of dementia and the care provision. It meant a transformation of psychogeriatric care and had to be implemented a new way of caring and supporting based on e-Health driving to the reduction of risk of infection of PwD. Appointments face to face were considered a risk for them because they have exposed to be infected by health team as frontline workers in the struggle to the virus. From the Psychogeriatry and Dementia Unit of the Valladolid and Zamora Hospitals, we had to change the way of working and change the traditional face to face care with tele-psychogeriatric care, which has been conducted through different forms: videconference, telephone, email, WhatsApp, and it has been implemented both in consultation and emergency care. Health workers of the nursing home have been changed the way for interacting and working with the specialized dementia team. It’s time for checking the changes made and the clinical worth of all of them in order to consider the choice of going back to the traditional care or maintain this new way of work. Even more, we need to know what we should change to the next outbreak and improve. We have made a poll among the workers of the nursing homes in order to know their perceptions about the specialized psychogeriatric care during the pandemic. Most of the workers have shown high satisfaction with the tele-psychogeriatric care received and agreed on the need to maintain this form of care in the future.

P24.2. Changes and new psychosocial and psychogeriatric approaches to people with dementia due COVID-19 outbreak in Spain

MUNOZ-SANCHEZ Juan-Luis1, PARRA-VIDALES Esther2, GOMEZ-SANCHEZ Sofia3, FRANCO-MARTIN Manuel1

1Hospital Universitario Rio Hortega, Valladolid, Spain, 2Fundación Intras, Zamora, Spain, 3Complejo Asistencial de Zamora, Zamora, Spain

There is large evidence that the services and supports based on model of PCC (Person Centred Care) improve quality of life and reduce disability of people living with dementia. How to manage PwD during Coronavirus outbreak has raised great concerns. In a nursing home, if there is a person infected, isolation precautions are recommended to prevent the spread between other residents and staff. Quarantine and isolation are highly effective tools in the control of infections but they have been difficult to implement effectively in nursing home unit dedicated to PwD. Their compromised cognitive functioning, insight and judgment impact their capacity to comply with restrictions. Moreover, complementary treatments or non pharmacological therapies such as occupational activities, multisensory stimulation like massage and face-to-face communication must be reduced or abolished. The same difficulty rises in psychiatric contests. If there are some Covid-19 cases in particularly in a special unit care for people with dementia, as documented by our experience could be very useful to share the accessible space in a Covid-in and Covid-free areas where people can move free minimizing risks and preserving freedom and independence. On the base of this strategy widespread screening may be required to have the early possibility to identify all positive residents, symptomatic and asymptomatic who need to be isolated. Managing people with dementia and behavioural disorders create great challenge. Education, some breaks and psychological support could be important tools to prevent the burn out. Psychologist can provide online consultation for the staff and for relatives. It's not necessary to avoid completely available non pharmacological activities but it's possible to choose those activities without direct physical interactions such as listen music, watch movies, read newspapers or novels. A strategy to avoid manipulation of materials between residents could be the creation of personal boxes for every resident. These boxes could be filled with preferred materials that will be used only to one person such as clothes, pencils, newspapers and so on. Create a separated facility for the covid positive patients permit the possibility to move free in the covid area, to have different night and day spaces and go on with meaningful activities this this approach can reduce delirium onset, sleep disorders and challenging behaviors. Moreover, the staff is less anxious, preserves a better relation with the residents and is more satisfied. Staff must develop a partnership with the patient relatives to share his/her individualized assistance plan and explain how the assistance in COVID area will be provided. Scheduling a time for a call, a video chat or a “window visit” may make it easier. Frequent contacts with the staff can also be useful as well phone call with the psychologist.

P24.3. The management of older people with Dementia and COVID-19 in nursing home

FABBO Andrea, BAGLIERI Annalisa, MANNI Barbara, PELLITTA Antonella, TURCI Marina

Health Authority and Services of Modena (AUSL), Modena, Italy

In the case of Spain hasn’t been different and COVID-19 outbreak has become a great challenge to the Spanish Health System. People with dementia (PwD) have been a group especially vulnerable to COVID-19 disease and relevant measures were taken for protecting them from the risk of being infected from the beginning. Lockdown most of the nursing homes, movements restrictions specially for the older people, limitation of the accessibility to the primary care centers changed the regular living of people of dementia and the care provision. It meant a transformation of psychogeriatric care and had to be implemented a new way of caring and supporting based on e-Health driving to the reduction of risk of infection of PwD. Appointments face to face were considered a risk for them because they have exposed to be infected by health team as frontline workers in the struggle to the virus. From the Psychogeriatry and Dementia Unit of the Valladolid and Zamora Hospitals, we had to change the way of working and change the traditional face to face care with tele-psychogeriatric care, which has been conducted through different forms: videconference, telephone, email, WhatsApp, and it has been implemented both in consultation and emergency care. Health workers of the nursing home have been changed the way for interacting and working with the specialized dementia team. It’s time for checking the changes made and the clinical worth of all of them in order to consider the choice of going back to the traditional care or maintain this new way of work. Even more, we need to know what we should change to the next outbreak and improve. We have made a poll among the workers of the nursing homes in order to know their perceptions about the specialized psychogeriatric care during the pandemic. Most of the workers have shown high satisfaction with the tele-psychogeriatric care received and agreed on the need to maintain this form of care in the future.
Introduction: The COVID-19 epidemic is still ongoing. It has brought new challenges and highlighted chronic problems. One of them in the Czechia has been the institutional long-term care.

Method: Data on the number of patients in various types of long-term care facilities are not available in Czechia. Therefore, case studies of care facilities and their responses to various degrees of anti-epidemic measures were chosen.

Results: Long-term care facilities were among most restricted during the corona crisis. These measures included lock-down, bans on visits etc. Moreover, some facilities responded by voluntarily preventive quarantine of all clients and employees for various lengths of weeks to months. Other facilities applied a strict anti-epidemic regime, and only obligatory restrictions.

Discussion: Experience of institutions providing care to vulnerable people, including people with dementia, indicate that the pandemic has revealed and accentuated many challenges, also the need for better health care for people with dementia and other vulnerable groups in residential long-term care facilities.

Conclusion: During the COVID-19 pandemic new topics and needs of research have emerged. In addition to biomedical ones, these are issues of care and organization, adequate support and psychosocial interventions in dementia care, but also preventing the spread of infection and optimizing epidemiologic measures to be effective and minimally restrictive. It is clear for the future that we need not only new and relevant scientific evidence but also its critical interpretation in the context of current knowledge and situation to provide optimal care also in long-term care facilities under new epidemiological conditions.

This session is organised by INTERDEM.
Quick oral presentations

QOP1. Quick oral presentations – Care approaches

**QOP1.1. Care in the times of COVID-19: counselling and intervention for vulnerable caregivers at Fundació ACE**

CANABATE Pilar\(^1\), BENAQUE Alba\(^1\), PRECKLER Silvia\(^1\), MORENO Mariola\(^1\), RODRIGUEZ Isabel\(^1\), ALARCON Emilio\(^1\), REEVES- GARAY Lola\(^2\), GURRUCHAGA Miren Jone\(^3\), TÀRRAGA Lluís\(^3\), VALERO Sergi\(^3\), BOADA Mercè\(^3\)

\(^1\)Fundació ACE. Institut Català Neurociències Aplicades, Barcelona, Spain, \(^2\)Trinity College London and University of Cambridge, Barcelona, Spain, \(^3\)Institut Català de Neurociències Aplicades, Barcelona, Spain

**Background:** Since 1996, Fundació ACE, a non-profit organization, has provided support and care following a holistic health model approach for people with dementia and their caregivers. Due to COVID-19 pandemic, ensuring such support to caregivers has represented a major challenge to our institution.

**Objectives:** To identify vulnerable caregivers’ main needs during lockdown and provide counselling, strategies and support to aid in the management of care during the pandemic.

**Methods:** Based on the FACE memory unit data base in 2019, 2,240 persons with dementia and at least one social-worker appointment, were identified. Among them, we identified caregiver vulnerability in 620 cases, according to the following selection criteria: caregiver on their own, overwhelmed/overworked caregiver, health-compromised caregiver/frailty syndrome, caregiver without emotional support network.

So far, Social-work team has performed 207 semi-structuredized phone interviews to identify specific needs of caregivers at risk under lockdown (April-May 2020). Actions taken involved personalized mentoring and counselling sessions.

**Results:** Sociodemographic data (63% women), identified needs and actions taken will be described. Main identified situations at risk are: psycho-emotional status (40%), care and control of dementia (20%), and lack of future action planning (12%). Analysis of needs and strategies (47% counseling, 31% education, 14% future planning) will be aligned with principles of relational intelligence, vulnerability perception, frailty syndrome, and individual/collective resilience.

**Discussion:** FACE’s approach to care in times of COVID 19 has not only provided a comprehensive intervention plan for vulnerable caregivers, but also has raised awareness of the importance of self-care at an emotional and personal levels to cope with their care duties. Such approach has led the implementation of tele-counselling, making us more accessible to caregivers; with the objective to identify hidden conditions of caregivers at risk and take action in a timely manner.

**QOP1.2. Withdrawn**

**QOP1.3. An innovative framework to support the development, implementation and evaluation of initiatives for prisoners with dementia**

BROOKE Joanne, HUGHES Anita

Birmingham City University, Birmingham, United Kingdom

**Background:** The prevalence of dementia in the prison setting is increasing due to the aging prison population with poor health (Brooke et al. 2018). Initiatives to support prisoners with dementia have been implemented. The aim of this study was to develop a framework to support the development, implementation and evaluation of initiatives for prisoners with dementia.

**Method:** The development of a framework from theoretical literature (Lee et al. 2016; du Toit and McGrath, 2019; du Toit et al. 2019), which was applied to evaluate initiatives to support prisoners with dementia. The framework consists of four main components including: 1) environment; 2) education; 3) meaningful engagement; 4) collaboration and support. Three initiatives were evaluated to explore the robustness of the framework: True Grit (Harrison, 2006); Special Needs Program for Inmate-Patients with Dementia (Hodel, 2009); and Gold Coats (Berry et al. 2006).

**Results:** The sub-components of each of the four components were further defined and refined during the evaluation process. The final framework consisted of: environment with 6 sub-components, which focused on the physical environment of the prison setting where the initiatives were delivered; education with 4 sub-components, focused on training and education of staff and prisoners regarding recognition of symptoms and supporting prisoners with dementia; meaningful engagement with 6 sub-components, focused on activities specifically for prisoners with dementia, and, collaboration and support with 4 sub-components, focused on collaboration of outside agencies, including health and social care.

**Conclusion:** The framework supports the development, implementation and evaluation of initiatives to support prisoners with dementia. The framework provides an understanding of the necessary components which need to be addressed in the development of initiatives, this process will ensure all basic
requirements are met, and prevent any oversight due to a focus on the needs of the prison system and a demonstration of positive outcomes.

**QOP1.4. Development and pilot study of the SPAN+ empowerment intervention for people with dementia living in the community**

VAN CORVEN Charlotte1, BIELDERMAN Annemiek1, GRAFF Maud1, LEONTJEVAS Ruslan2, LUCASSEN Peter3, GERRITSEN Debby1

1Radboud University Medical Centre, Radboud Alzheimer Centre, Nijmegen, Netherlands, 2Open University, Heerlen, Netherlands

**Background:** Empowerment is seen as a promising concept in dementia care. In our previous study, we found that four themes are important to empower people with dementia: (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) remain a sense of worth. The aim of this study is to develop and pilot-test an empowerment intervention for people with dementia living in the community.

**Methods:** The Intervention Mapping framework was used. We conducted thirteen focus group discussions and three interviews with people with dementia, their family caregivers, and healthcare professionals to explore needs and wishes. An advisory expert team was involved in all project phases, and assured that the design of the research project, data collection and intervention design was suitable for all stakeholders. Three persons with dementia participated in the pilot study, together with their family caregiver and healthcare professional.

**Results:** We developed the SPAN+ intervention that aims to reflect and act on wishes and needs of people with dementia and their family carers regarding the four themes of empowerment. The intervention makes use of a set of conversation cards. These encourage the person with dementia and their family caregiver to converse about the four themes of empowerment. Together with a healthcare professional, objectives are formulated for each of the four themes. Preliminary results of the pilot study showed that participants enjoyed using the conversation cards and the conversations with their healthcare professional.

**Conclusion:** We developed an empowerment intervention that supports people with dementia to go into conversation about the four themes of empowerment. The overall experience of people with dementia, their family caregivers and healthcare professionals was positive. Further research is needed to test the effectiveness and feasibility of the SPAN+ intervention.

**QOP1.5. Transforming care for people with advanced dementia in care homes: process evaluation of Namaste Care Intervention UK (NCI-UK)**

LATHAM Isabelle, BROOKER Dawn

Association for Dementia Studies, University of Worcester, Worcester, United Kingdom

**Namaste Care was developed initially in the USA by Joyce Simard, (2013). A daily programme of physical, sensory and emotional care supports people living with advanced dementia to engage with carers, family and their surroundings. However, implementing change in practice is challenging for care homes. This presentation reports on a 3-year process evaluation of Namaste Care within 6 UK care homes. The NCI-UK study created an evidenced framework of essential elements forming a UK-model of Namaste Care. The study investigated the feasibility of implementation, including organisational facilitators and barriers, cost implications and outcomes for residents, family and staff.**

6 care homes, representing varied size/registration, were provided with standardised training and implemented Namaste Care once or twice daily for residents with advanced dementia. Interviews, diaries and observations explored the impact and experience of implementation (acceptability, feasibility, cost and development). Resident data on medication use (analgesia, anti-psychotics, sedation); untoward incidences (falls, accidents); service use (unplanned hospital admission); and measures of agitation and quality of life were collected monthly. Daily recording of intervention delivery and staff views of impact on participating residents were undertaken.

5 of 6 care homes successfully implemented Namaste for a 3-6 month period undertaking 523 sessions in total. Qualitative and quantitative data was collected from 52 residents, 27 staff and 10 family carers. Data suggests a positive impact on residents on several measures for little additional cost. Reorganising day-to-day care to incorporate Namaste Care is challenging, although care homes demonstrated similar key strategies for successful implementation. The study concluded Namaste Care is feasible to implement in UK care homes and appears to be beneficial for supporting improved social, emotional and psychological support for people living with advanced dementia. Implementation requires planning, purpose and persistence and these need to be considered an integral part of the intervention itself.

**QOP1.6. Proven feasibility of the FindMyApps tablet-based intervention to promote social health in dementia**

NEAL David1, KERKHOF Yvonne2, BEENTJES Kim1, KOHL Gianna3, BERGSMA Ad2, MULLER Majon1, ZWAN Marissa1, GRAFF Maud4, DROES Rose-Marie1

1Amsterdam UMC, Amsterdam, Netherlands, 2Saxion University of Applied Sciences, Deventer, Netherlands, 3University College London, London, United Kingdom, 4Radboud UMC, Nijmegen, Netherlands

**Objectives:** FindMyApps comprises two components: 1) a tablet-based app to help people with dementia or mild cognitive impairment (MCI) find user-friendly apps for self-management and social participation;
and 2) training for caregivers to use errorless learning principles to support the person with dementia’s learning process. Two pilot studies investigated the feasibility of implementing this complex intervention and of evaluating it in a randomized controlled trial (RCT).

Methods: Two consecutive pilot RCTs (n1=20 and n2=59) and parallel process evaluations were conducted following Medical Research Council (MRC) guidance for evaluating complex interventions. Dyads (person with dementia and their caregiver) were randomly assigned to receive FindMyApps or a control intervention (normal tablet with general advice). Validated questionnaires were used for baseline measurements and at three-month follow-up. Post-test semi-structured interviews were conducted with a purposively selected sample of participants.

Results: In both studies, most participants learned to use the FindMyApps app. Many required ongoing caregiver support. Errorless learning was experienced as helpful but training was implemented inconsistently. Some participants found the questionnaires too long. As anticipated, no statistically significant between-group differences were found regarding primary outcomes (first pilot, n=20). However, using FindMyApps may have improved aspects of self-efficacy and self-management (effect size hp2 range 0.12 to 0.42). FindMyApps seemed to support engagement in meaningful activities (second pilot, n=59). Drop-out rates were 37.5% and 12.1% respectively.

Conclusion: The intervention and research method were revised for a definitive randomized controlled trial: the app was optimized for tablet use, training was improved, and interviews shortened. Based on demonstrated feasibility, a definitive RCT in community-dwelling people with MCI or mild dementia started in spring 2020 (target n=150 dyads; 75 experimental, 75 control).

The pilot studies were conducted with funding from Association to Support VCVGZ and H2020-MSCA-ITN-2015 (INDUCT; 676265). The definitive trial is financed within H2020-MSCA-ITN-2019 (DISTINCT; 813196).

QOP1.7. Cost-consequence analysis of the Partner in Balance support program for informal carers of persons with dementia

Objective: To perform a cost-consequence analysis of the blended care self-management programme Partner in Balance (PiB) for informal caregivers of people with early-stage dementia. This information could support decision-makers to consider reimbursing PiB in practice.

Methods: Alongside a randomized controlled trial we measured costs and consequences of PiB (face-to-face coaching combined with tailored web-based modules; n = 41) versus care as usual (n = 39). Data were collected at baseline and after 8 weeks. Quality of life was measured with ICECAP-O with UK index values to obtain utilities. Formal and informal care use by the caregiver and care recipient were obtained by the RUD-lite and multiplied with standard Dutch unit prices to obtain care costs. The intervention effect was estimated by a regression model including intervention arm and baseline value.

Results: A significant increase of quality of life in favour of the intervention group was demonstrated at 8-week follow-up. The change in utilities was significantly higher in the intervention group (+0.063), corresponding with significantly quality-adjusted life years increase of 0.005 over an 8-week period. The change in number of mental health consultations was significantly lower (-1.2 consults per participant) in the intervention group. Total costs did not significantly differ between the groups. The incremental cost-effectiveness ratio was €113,223 per QALY. This is higher than the adopted cut-off of €40,000 per QALY. However, the uncertainty of the mean incremental costs per person over the 8-week period was very large.

Conclusions: From a clinical viewpoint, PiB can be recommended as it significantly increased quality of life over an 8-week timeframe. From a health-economic healthcare perspective, the added value of PiB is not demonstrated on the short term. Future studies including long-term follow up could clarify if the short-term increase in health status could lead to a decrease in long-term medical consumption.

QOP1.8. Psychosocial support for people with dementia and their caregivers: building bridges between consisting initiatives of care and needs

VAN DER SCHOT Astrid1, VAN BELZEN Elsemieke1, BOOTS Lizzy2, GRAAFF Maud3, VAN DER ROEST Henriette4, HARTSTRA Egbert4, GROOT ZWAATINK Rob5

1Trimbos-instituut, Utrecht, Netherlands, 2Dr., Maastricht, Netherlands, 3Prof. dr., Nijmegen, Netherlands, 4Dr., Utrecht, Netherlands, 5MSc, Amersfoort, Netherlands

Background: People with dementia and their caregivers need (psychosocial) support for living with dementia or caring for a relative with dementia. Many psychosocial interventions for dementia are available in The Netherlands, but it is unclear if these interventions meet existing needs. In addition, caregivers often are unaware of the availability of these interventions, or do not know how to get access to them. Information on interventions is fragmented and can be found at various online sources. Caregivers prefer to have one digital overview of existing interventions. The aim of this study is to identify the needs of people with dementia and their caregivers and match these needs with existing psychosocial
interventions. A clear and concise overview of available interventions is needed. Different phases of dementia and specifically the needs of young people with dementia and/or people with dementia and a migration background and their caregivers are also considered.

Method: A literature search on needs of people with dementia and their caregivers and existing interventions was performed from literature that was published between 2010 to 2020. Consulted databases included Pubmed, CINHAL, PsychInfo and Dutch databases. The results of these searches were supplemented by information collected by Alzheimer Nederland among professionals, people with dementia and their caregivers. Finally, interventions were linked to specific needs they address.

Results: The study will provide an overview of specific needs for which psychosocial interventions are available, which will be published on the online platform of Alzheimer Nederland (www.dementie.nl). The study will also provide insight into current gaps in the offer of psychosocial interventions for dementia and will give directions for future development and deployment of effective interventions. The results of the needs inventory, the match with existing psychosocial interventions and the resulting gap will be presented.

QOP1.9. À la recherche du temps perdu: music therapy for people with dementia (PwD) and their caregivers

BARTORELLI Luisa, RAGNI Silvia, HAERING Sylvia
Alzheimer Uniti Roma, Roma, Italy

It is well-known how the relationship between PwD and caregivers affects quality of life of both, as the disease progresses. It is also well-known that Music Therapy for PwD has shown increasingly satisfactory results. This quantum-qualitative research project, supported by Waldensian Church, and led by Alzheimer Uniti Roma within a Memory Café, uses music to improve this relationship. The objective for PwD are cognitive stimulation and well-being through music, for caregiver is to promote an effective communication with the person, away from daily management of the disease. For both, there is the goal of getting away from isolation and being able to socialize on equal terms.

Materials and Method: 19 two-hour meetings, twice a month over a 12-month period. A multi-professional group led by a music therapist and a psychologist, following an active method, play Orff instruments and violin with participants. Activities are singing, movement inspired by music, improvisation with instruments, listening and sharing impressions verbally. Maximum number is 37 participants (18 PwD and 19 caregivers), including spouses, sons, daughters, family assistants and friends, with an average of 18 participants per meeting. Quantitative analysis is through the Canterbury Wellbeing Scales (CWS), measuring 5 aspects of well-being in the PwD and the caregiver, both pre-and post-session. Family members receive an exercise book to continue activities at home.

Results: The CWS shows significant differences between entry and exit measurements in the well-being in both PwD and caregivers. The effect continues in follow-up. The qualitative analysis shows that PwD are less anxious and more communicative and caregivers are more aware and comfortable.

Conclusion: The data shows that Music Therapy set up with an accurate methodology and conducted in favourable surroundings such as Memory Cafés, promotes inclusion and improves relationships and quality of life for PwD and caregivers. Results will be presented in video.

QOP1.10. Development and assessment of feasibility of psychosocial intervention SOCAV-in-Primary-Care

DAS Phèbe1,2, ROETS-MERKEN Lieve3, GRAFF Maud3
1Radboudumc, Nijmegen, Netherlands, 2MSc, Nijmegen, Netherlands, 3PhD, Nijmegen, Netherlands

Background: There is a need of feasible and effective interventions to support community-dwelling people with dementia and their caregiver. If more person-centered care would be offered at home, their sense of dignity, self-reliance, autonomy, daily functioning and quality of life might increase. The psychosocial intervention “SOCAV-in-primary-care” (SOCAV-PC), is such a program. SOCAV was successfully tested in nursing homes and involves a training and coaching to nurses and nurse-assistants in supporting persons with dementia and their caregivers to maintain or improve their self-reliance, daily functioning in meaningful activities and quality of life. The aim of this study was to investigate which elements could improve the likelihood of success of the SOCAV-PC program, and to evaluate its feasibility.

Methods: SOCAV-PC was developed and its feasibility assessed according to the MRC guidelines for complex interventions. In phase 1, the developmental phase, qualitative data on the participants’ needs, and the eligibility and elements for success of the contents and delivery of the draft intervention was collected in focus group interviews with caregivers and homecare professionals separately, and in individual interviews among persons with dementia. Phase 2, feasibility was evaluated in a pilot study in terms of acceptability, demand, implementation and practicability of the SOCAV-PC program. Data was derived from (1) intervention and coaching diaries from the homecare professionals, (2) coaching diaries of the coaches, (3) monitoring of testing procedures and (4) focus groups among caregivers and homecare professionals, and (5) individual interviews with participants with dementia.

Results: Results will be presented and discussed at the conference.
Conclusion: The results of this study will inform the design for part 2 of the feasibility phase, the pilot effectiveness study.

QOP1.11. Withdrawn
QOP1.12. Therapeutic dance movement for mild cognitive impairment patients

MÄGI Mari-Liis, KAARMA Katrin
Dementia Competence Centre, Viljandi, Estonia

There are agreed benefits of early noticing and diagnosing cognitive decline. Mild cognitive impairment (MCI) is a syndrome defined by clinical, cognitive, and functional criteria. Growing scientific evidence shows that physical and psychological interventions targeted at people with MCI will enable better quality of life for them and may slow down progression in cognitive decline.

The Estonian Dementia Competency Centre is promoting psychosocial interventions for MCI patients. One of the pilot projects was dancing. Based on scientific literature, dance movement based intervention is outstanding as it influences emotional, social, physical and cognitive domains.

The objective of the project was to assess, whether dance movement based activity is acceptable and suitable for elderly with MCI and whether this intervention improves their psychosocial wellbeing. Based on a screening tool (Montreal Cognitive Assessment; MoCA) for determining cognitive decline two groups of people were formed. Control group was formed of people without cognitive decline (MoCa score 26 or higher) and the test group consisted of people with MCI (MoCA score under 26 but higher than 20). Baseline assessments of all participants’ general health, cognitive and emotional status and physical ability were carried out. Dance movement training sessions were taking place twice a week during 12 weeks. The same measurements were carried out for the participants after 12 weeks. The drop-out of participants was substantial but it was equal for MCI and non-MCI persons. 24 participants were selected and assessed; 20 started dance lessons and 12 of them finished it after 12 weeks. The overall reported subjective psychosocial wellbeing and physical ability improved. Participants assessed the activity as rewarding and pleasant. They pointed out the benefit of good social contacts and support. The improvement of physical performance specially balance and coordination improved subjectively and visually during the dance movement based activity.

QOP2. Quick oral presentations – Care services

QOP2.1. Before the end of life in patients with Alzheimer's disease

IOANCIO IOANA, SPIRU LUIZA
Elias Emergency Hospital, Bucharest, Romania

Alzheimer’s disease is considered a neurocognitive disease with a slow evolution, experiencing a plateau in development when patients have been diagnosed early, have followed a closely monitored treatment and have been constantly clinically reevaluated. Support, both medical and from the family of the patient, are the key for a prolonged evolution of this irreversible illness.

Aims: Our study’s primary objective was the gerontopsychiatric evaluation of the final period of life of patients with Alzheimer’s disease, within the acute and hospital care cadre.

Methods: Our study was fulfilled in the Memory Clinic, Elias University Emergency Hospital, Bucharest, Romania, in the years 2017-2020. 117 patients diagnosed with Alzheimer’s disease, 77% women and 23% men, aged 72 years and over were enrolled in the study using international diagnostic criteria. We evaluated the patients as well as yearly and the next three years follow-up.

Subject evaluation was performed by a complex neuropsychological battery: Standardized Geriatric Evaluation.

Results: In the final months of life, patients admitted to our clinic have described three kinds of evolution. In one group, patients have resignedly looked towards the end, expressing requests to return “home”, in the company of their closest relative and with their favourite food. Another group has presented episodes of delirium, with psychomotor agitation and reversal of their sleep-alert schedule. The majority of patients met their end through comorbidities: sepsis, strokes, cancer or cardiovascular pathologies.

Conclusions: Patients with Alzheimer’s disease that are correctly treated and monitored meet their end through different pathologies, the most frequent being intercurrent infections, respectively sepsis. In the brief moments of lucidity, they evoke the image of their home.

QOP2.2. Dementia-sensitive design of the physical environment in 10 care facilities in Bavaria. Small tools with a substantial impact

DIETZ Birgit
TU München, Munich, Germany

As part of a research project in Bavaria, ten very different care facilities were invited to investigate whether their buildings, rooms and outdoor areas were “fit” for the needs of their residents. After training on “desired” requirements and the “actual” situation, recommendations were made and implemented. The
facilities were supported and monitored for three years. It became clear that simple measures that were easy to implement resulted in a noticeable improvement for residents, employees and relatives.

The residents' home is also the staff's workplace. Therefore, the working groups were set up to include as many users (representatives for the residents, nursing staff, housekeeping and cleaning staff, caretaker, administrative staff and nursing managers) as possible in the process. Not only are all facilities home to residents from very different walks of life, they also employ staff with a wide range of experience in a variety of positions. Consequently, in each facility views of which action was required were initially quite different. We anticipated big differences in opinion in terms of prioritizing the implementation of our recommendations. A better shared understanding of the specific physical, mental and emotional situation of the residents and their special needs in terms of the design of their physical environment was achieved. Obstacles in implementing such design changes were discussed. An analysis of the measures most frequently recommended in the ten participating facilities shows that they are similar. Acoustics, light and signage were at the forefront, followed by open space design. This suggests the most successful measures incorporated as part of dementia-sensitive design in care facilities is generally transferable.

It was evident that in all facilities there is a need to raise awareness and ensure a continuous transfer of information to facilitate age- and dementia-sensitive architecture in the long-term.

**QOP2.3. Success factors of dementia friendly initiatives using realist review and -evaluation**

**THUISSEN Marjolein**1, KUIJER-SIEBELINK Wietse2, LEXIS Monique3, PETERS Jose2, RIANNE Janssens4, NIJHUIS-VANDERSANDEN Ria5, CHADBORN Neil6, RADFORD Kate6, JUSTINE Schneider6, RAMON Daniels3, LOGAN Pip7, MAUD Graff8

1Radboudumc, Nijmegen, Netherlands, 2dr., Nijmegen, Netherlands, 3dr., Heerlen, Netherlands, 4Msc., Heerlen, Netherlands, 5Prof. dr., Heerlen, Netherlands, 6dr., Nottingham, United Kingdom, 7Prof. dr., Nottingham, United Kingdom

Dementia friendliness is a concept that underpins communities and initiatives that promote inclusion of persons with dementia and their carers. Mentality is a project that studies successfactors of dementiafriendly initiatives and -communities in three phases, using the realist approach. The main goal in a realist approach is to illuminate ‘what works, for whom, under what circumstances, and how, as understanding these processes is important for informing policy and practice in terms of what helps or hinders successful and sustainable development of dementia friendly initiatives across different contexts.

In phase A, we conducted a realist review literature of community dementia friendly initiatives to develop understanding about the outcomes for persons with dementia and their caregiver and the key factors in achieving them. In phase B, we focused on key factors in developing and sustaining dementia friendly initiatives, using Dutch best practices. The ongoing work of Phase C is to implement these findings across multiple sites in Netherlands.

In Phase A, of the initial 6736 search results, 29 studies were included based on in/exclusion criteria. Data synthesis resulted in three midrange program theories, explaining how contexts and mechanisms produced outcomes for persons with dementia and caregivers. In phase B, a multiple case study was undertaken using interviews, observations and documentation from with 30 stakeholders from 4 Dutch best practices of dementia friendly communities. A realist logic of analysis within and across the cases resulted in six realist program theories, explaining how context and mechanisms produces outcomes for professionals, volunteers, persons with dementia and their caregivers in creating dementia friendly communities.

In this presentation, the realist program theories of phase A and B will be presented and discussed together with the protocol for phase C

**QOP2.4. Sensory gardens in dementia care: will they survive the Covid-19 pandemics?**

**PROLO Paolo**1, SASSI Enrico2

1Swiss federal disability insurance, Bellinzona, Switzerland, 2Architect, Lugano, Switzerland

Since September 2014, 75 elderly people have enjoyed a sensory garden in a daytime health care center in Balerna in southern Switzerland almost all year long. Sensory gardens are supposed to be beneficial to improve mental well-being in vulnerable people. All subjects were diagnosed with Senile Dementia of the Alzheimer’s Type (SDAT) according to established criteria (Age: 69-89 yrs.; 20 males; 55 females). We already showed that the garden counterbalanced aggressiveness and anxiety. 55/75 people attending the garden from September 2014 until the first week of March 2020 enjoyed the scents and fresh air. Since then and several weeks thereafter, the daycare center and garden were closed due to the Covid-19 pandemic. This has suddenly changed one’s target to social distancing. Although video calls and tablet application has showed positive behavioral effect in nursing homes, one cannot confine individuals indoor forever. The garden is composed of two areas with different functions and appearances: the system of ramps and a ring circuit. 60/75 users enjoyed the most walking the ramps like it were their way home. The only gathering point was represented by a water fountain where all 75 subjects drank fresh water. Non more than 2 or 3 people together were observed at any time close to the fountain by caregiving personnel. Moreover, no more than 8 people were admitted to the garden at any time. This was due to the center’s standard timing and regulations. We could not demonstrate any improvement in social interactions. In conclusion, at the present time the garden will still provide a kind of sensitive stimulation and represent a
psychosocial intervention that can be delivered by non-fully specialist healthcare without enhancing an unrequested health risk.

QOP2.5. Withdrawn

QOP2.6. Mapping models of residential respite services in England for people living with dementia and their carers

COLE Laura, COLE Laura, ORELLANA Katharine, MANTHORPE Jill, SAMSI Kritika
King's College London, London, United Kingdom

Residential respite care, or a short stay in a care home, can be beneficial for people living with dementia and their carers. It provides them both with a break and is seen as a way of supporting people living with dementia to stay at home for longer, potentially delaying a move to a care home. However, little is known about respite services on offer, especially in terms of availability, access, service provision and cost. The first part of this two-year study aims to 'map' or identify the different models or types of residential respite available to people living with dementia and their carers across England. This was achieved by 1) asking residential respite providers to complete a short mapping template detailing the service they provide (including questions about number of places available, minimum or maximum lengths of stay, how the service can be accessed and who pays); and 2) conducting a stakeholder workshop with social care practitioners, providers and commissioners of residential respite services to discuss the key issues. The information gathered from these two methods are currently being collated, themes or consistencies will be drawn out and presented. We will also discuss the second part of the study in which we aim to interview 80 people living with dementia and their carers about their views, expectations, and experiences of residential respite.

QOP2.7. Importance of ergonomic interventions at the living space

ANAGNOSTOPOULOU Konstantina
Occupational therapist, Athens, Greece

Occupational Therapy is a health science that is increasingly concerned with improving a person's quality of life with dementia. One of the main points of interest in geriatric occupational therapy is the proper configuration of the individual's living space. Below are basic suggestions for ergonomic arrangement of the space, so that the daily life of the person becomes more functional and easy.

The basic condition for the amendments is that the person be autonomous and not in need of supervision. The place must be organized in such a way that it is functional, simple, efficient and safe for the person with dementia. General recommendations for the whole house are the correct placement of the furniture so that it is not difficult to move around the house. All doors should have a sticker indicating or depicting which room it is. Gathering basic items such as keys, phone, wallet and more at a specific location would be helpful. Equally important would be the existence of a notebook in a fixed location where the person's daily schedule would be recorded as well as emergency telephones.

It is important not to omit these and other interventions, which may be related to the kitchen, bathroom and any room in the house. By changing the place, reduces the stress of everyday life, the lack of orientation, and simplifies the daily activities inside the house, making them easier and safer. In addition, interfering in the place prolongs the autonomy and independence of the individual.

In summary, there are many more ergonomic arrangements that are tailored to each person's needs. The main concern of every occupational therapist is to assess the needs and to improve in every way the quality of life of the person with dementia, his autonomy and the disposition for life.

QOP2.8. Improving night care for community dwelling people with dementia

COUPRY Olivier, MOUACI Catherine
Fondation Médéric Alzheimer, Paris, France

Introduction: Night care for community dwelling people with dementia are still little or not covered by an adapted aid or care device. However, the end of the day and the night are sensitive times when several difficulties may arise which can increase the burden of caregivers and precipitate institutionalization. It can also lead to dramatic accidents or deprivation of liberty. Caregivers are also affected by these situations, which are often a breaking point in home life.

Methods: In March 2018, the Fondation Médéric Alzheimer launched a call for projects "Alzheimer: improving night-time support for people living at home". Four projects have been selected and are currently being supported until the end of 2020. Two projects are home-based support and two projects offer overnight accommodation in a gerontological establishment. These projects provide respite and advice to caregivers and are an opportunity to offer quality personalized support to people with dementia. Projects are being monitored in parallel by a firm specialising in social and medico-social evaluation. Data collection is based on questionnaires, observation grids and interview for people with dementia, caregivers and professionals. Effectiveness, impact measure, conditions for sustainability and cost/benefit ratio will be analysed.
Results: Intermediate results are encouraging. Final results are expected by December 2020. They should lead to a publication and the elaboration of a guide for future project leaders, decision-makers, funders and direct beneficiaries based on the lessons learned from these projects.

Conclusion: Safety and quality of life of people with dementia depend to a great extent on the care given to usual living environment. The professionalization of night care can be one of the keys and is a priority for people still living alone at home. It can also be a way to delay institutionalization, reduce night-time incidents, reduce costs and ease the burden on caregivers.

**QOP2.9. France Alzheimer’s vacation retreats**

**GILLY Lorène**

France Alzheimer and related diseases, Paris, France

Organizing vacation can be so taxing for people living with dementia and their families that it sometimes seems easier just to not go. And yet, those people are very much in need of vacation! Time off is an essential respite in their fight with the disease and gives them the energy to face the daily challenges it poses. Those fighting Alzheimer’s want the same vacation as anybody else. Hiking and tanning on the beach are examples of the little things which are highly appreciated by families.

To make it possible, they need the appropriate assistance. This is why vacation retreats have been one of France Alzheimer’s main focuses for the past 30 years.

Every year, from April to October, about 15 trips are organized by the Association in centers which are adapted for people with dementia and their caregivers. The retreats last for 10 or 11 days. Accommodation, full board, activities and excursions are all covered. Last year, 17 trips were organized for a total of 433 participants.

Thanks to France Alzheimer’s volunteers, who take charge of the entire organization, guests can relax while receiving the care they need. Stigmatizing the families is out of the question; quite the contrary, since the objective of these retreats is to focus on other things than the disease.

More than 6,000 people have benefited from vacation retreats over the past 30 years.

An affordable price

In order to reduce vacation access inequalities and to grant this opportunity to as many people as possible, France Alzheimer offers 5 pricing plans. They are proportional to the participants’ yearly income tax. In other words, the cost is adapted to the income of those who wish to benefit from the retreat. The difference between the actual cost and the paid amount is covered by the Association.

**QOP2.10. Uncovering variation in care; the first English national memory service case note audit**

**COOK Laura, ISAACS Jeremy**

NHS England and Improvement London Region, London, United Kingdom

In England, dementia is predominantly diagnosed in memory services operated by mental health providers. There is limited data comparing practices between services. In 2019, memory services across England were invited to participate in a national audit comprising a case note audit of 50 consecutively seen patients.

85 out of approximately 215 memory services in England participated, contributing data on 3,978 patients. Results demonstrated significant variation in assessment, diagnostic and post-diagnostic practices. 57% of patients were asked about their hearing and 61% about their vision. The proportion of patients deemed not to require neuroimaging varied between services from 0% to 92%. 2% of patients were referred for a specialist investigation (PET scan, DAT scan, CSF examination). The proportion of people aged ≥ 65 diagnosed with mild cognitive impairment (MCI) varied from 0% to 47% and with any dementia from 22% to 100%. Among patients with dementia, the proportion given a vascular dementia sub-type varied from 0% to 43%. Overall, 7% of patients with dementia aged < 65 and 0.3% of those aged ≥ 65 were diagnosed with frontotemporal dementia. Average time from referral to diagnosis varied from 3 weeks to 34 weeks. Around a quarter of services were unable to provide cognitive stimulation therapy or carer psychoeducation. 36% of people with dementia were offered the opportunity to provide consent to be contact for research.

Key areas identified for quality improvement at a national post-audit meeting included: creating local memory service forums, improving liaison with neurology and neuroradiology, improving physical health assessments, creating a ‘consent to contact’ research script, reducing waiting times and training on recognition of MCI and frontotemporal dementia.

To our knowledge this is the first national memory service case note audit in England. It has enabled services to benchmark their performance and identified key areas for quality improvement.

**QOP2.11. The effects of computerized cognitive training with whole body cryotherapy on cognitive functions in seniors**

**SENCZYSZYN Adrianna, WALLNER Renata, SZCZEŚNIAK Dorota, ŁUC Mateusz, RYMASZEWSKA Joanna**
Background: Subjective Cognitive Decline (SCD) and Mild Cognitive Impairment (MCI) are common in the elderly population and represent a high-risk group for progression to dementia. Innovative, complex and engaging non-pharmacological methods of cognitive stimulation implementable at this stage are needed.

Methods: A 9-week single-blind pre/post case-control trial was conducted. The study enrolled 84 adults aged 60 or older and allocated them into one of two intervention group: EG1; CCT with psychoeducation, EG2; CCT with psychoeducation and 10 WBC sessions, or control group (CG), who were the usual care users. The primary outcome measures were cognitive functions evaluated with Montreal Assessment Scale (MoCA) and several other neuropsychological tools (e.g. SCWT, selected tasks from RBANS). The depressive symptoms assessed with Geriatric Depression Scale (GDS) were secondary outcome measures.

Results: The results show evidence for increased performance in the assessment of general cognitive functioning in both EGs (p≤0.05). Significant improvement was also visible in several cognitive domains such as: verbal fluency (EG1 and EG2), learning ability and immediate memory (EG1 and EG2), delayed memory (EG2), attentional control (EG1) and information processing (EG2) (p≤0.05). However, only in the group with combined interventions (CCT+WBC) participants presented significantly less depressive symptoms (p≤0.05).

Conclusions: Results from the study suggest that CCT, especially in combination with WBC, might be a practical and effective method of improvement in cognitive performance. Moreover, this combination seems to lead to a reduction of depressive symptoms.

QOP2.12. Blood biomarkers and cost and wait time for diagnosing treatment-eligible patients for Alzheimer’s disease

MATTKE Soeren1, CHO Sang Kyu1, BITTNER Tobias2, HLAJAK Jakub1, HANSON Mark1

1USC, Los Angeles, United States, 2Roche, Basel, Switzerland

Background: A disease-modifying treatment (DMT) for Alzheimer’s (AD) might become available soon. Concerns have been raised that the large number of patients might overwhelm the healthcare system, because of scarce dementia specialists. Blood based biomarker (BBBM) tests for the pathologic hallmarks are a promising tool to improve triaging at the primary care level. We simulated their impact on cost and wait times.

Methods: We simulate the U.S. population age 50+ over 30 years combining a disease progression model and a system dynamics model for capacity constraints (specialist cognitive testing and confirmatory biomarker testing with PET or CSF). We compare four scenarios for primary care evaluation (1) cognitive screening only (MMSE), (2) BBBM only, (3) MMSE followed by BBBM if positive and (4) BBBM followed by MMSE if positive. Parameter were derived from published data and assumptions.

Results: Using MMSE or BBBM alone would result in specialist referrals that are projected to continuously exceed capacity from 2020 to 2050. Combining MMSE and BBBM in either order would eliminate wait lists after three years. Projected number of correctly identified cases (i.e., true positive for MCI due to AD) will increase from ~480,000 for MMSE or BBBM alone to ~600,000 for MMSE and BBBM combined on average each year. Average cost per year would be an estimated $7.2 billion for MMSE alone, $7.5 billion for BBBM alone, and $6.8 billion for MMSE and BBBM combined, and cost per correctly identified case will decline from ~$15,000 for MMSE or BBBM alone to ~$11,000 for MMSE plus BBBM.

Conclusions: Combining BBBM with MMSE is projected to increase efficiency and value of the triage process for DMT eligibility at the primary care level, as the addition of a BBBM would reduce wait times for specialist visits and diagnostic yield dramatically without increasing net cost.

QOP3. Quick oral presentations – Medical and public health aspects

QOP3.2. The electronic Person-Specific Outcome Measure (ePSOM) development programme

SAUNDERS Stina1, MUNIZ-TERRERA Graciela1, EVANS Alison2, SHEEHAN Shane1, LUZ Saturnino3, RITCHIE Craig4

1University of Edinburgh, Edinburgh, United Kingdom, 2Alzheimer's Research UK, London, United Kingdom

Introduction: There is a recognition that outcome measures currently used in clinical trials in prodromal and preclinical neurodegenerative diseases do not capture the research participants’ views of effectiveness. This led to the four stage ePSOM programme [1] an evidence review and programme methodology; [2] focus groups to identify key domains of importance to people at various degrees of
neurodegenerative disease; [3] a UK-wide online survey and [4] the development of an app which will permit the design of an outcome measure for use in regulatory trials.

Aim: To understand the outcomes that matter to individuals in Alzheimer’s disease clinical trials and ultimately to develop a patient reported outcome measure, an ePSOM app.

Method: The first three stages of the programme are completed. Here, we report the overall approach to the programme and focus particularly on the UK wide survey. Our mixed methods online survey collected information on sociodemographic background, brain health and individuals’ views across five key domains. The survey data was analysed using clustering and natural language programming techniques.

Results: Our literature review showed Alzheimer’s disease trials currently do not use any patient-reported outcome measures. Our focus groups (n=41) yielded five key domains in relation to what matters to people when developing new treatments for Alzheimer’s disease. 5807 people completed the survey. Most were female (76.9%), married (63.4%) and living in an urban area (61.8%). The mean age in women was 57.35 (SD=13.8) and 62.88 (SD=13.08) in men. 73% had supported a relative with dementia but only 15.4% had sought help for their own brain health. The largest cluster of responses are associated with “Reading” this cluster accounts for 3107 of the answers given. Closely followed by “Car/Drive” with 2969 answers. Other clusters identified with above 1000 answers are “Walk”, “Garden”, “Cook”, “Understand”, “Chat”, “Remember” and “Shop”.

QOP3.3. Can an early diagnosis of dementia help people to live longer? A study of electronic health care records

COUCH Elyse, MUELLER Christoph, PERERA Gayan, LAWRENCE Vanessa, PRINA Matthew
King’s College London, London, United Kingdom

Background: Diagnosing dementia early is a cornerstone of many European National Dementia Strategies. However, without reliable biomarkers or diagnostic tests, diagnosing dementia early and studying its potential benefits is challenging. Mild Cognitive Impairment (MCI) is considered to be prodromal to dementia, therefore a diagnosis of MCI could facilitate an earlier diagnosis of dementia. Similarly, studying people with dementia who received a diagnosis of MCI before dementia presents researchers with the opportunity to explore the benefits of diagnosing dementia early.

Aim: This study aimed to test whether a diagnosis of MCI before dementia can be used as an indicator for early diagnosis. Additionally, we investigated whether people with an early diagnosis of dementia had a reduced risk or mortality.

Methods: We studied the medical records of 18,557 people who had been diagnosed with dementia by South London and Maudsley NHS in London. Participants were divided into two groups: those who were diagnosed with MCI before their dementia (referred to as the early diagnosis group) and those who were not. We compared the profile of dementia-related symptoms at dementia diagnosis and tested whether those with an early diagnosis had a reduced risk of mortality.

Results: 5.5% (1,030) of participants in our sample had an early diagnosis of dementia. People with an early diagnosis had fewer cognitive, functional, and psychiatric problems at dementia diagnosis. Participants with an early diagnosis also had a 14% reduced risk of mortality, when adjusting for physical and mental health and physical functioning.

Conclusions: A diagnosis of MCI before dementia is a useful proxy for investigating the benefits of diagnosing dementia early. In this sample, an early diagnosis was associated with a reduced risk of mortality. Understanding the benefits of diagnosing dementia early could help people with suspected dementia make an informed decision about when to seek a diagnosis.

QOP3.4. How is migration background considered in the treatment and care of people - a comparison of national dementia care guidelines in Europe

SCHMACHTENBERG Tim¹, MONSEES Jessica¹, WOLFGANG Hoffmann¹, VAN DEN BERG Neeltje², STENTZEL Ulrike², THYRIAN René¹
¹German Center for Neurodegenerative Diseases, Greifswald, Germany, ²University Medicine Greifswald, Institute for Community Medicine, Greifswald, Germany

Background: People with migration background (PwM) are a vulnerable group regarding dementia. Providing care for them is a public health challenge in Europe. Many countries are issuing care guidelines, but a systematic overview of their migration reference is lacking. This study aims to determine the extent to which care guidelines consider PwM, which migration-related content focuses are set, and whether recommendations are made to ensure appropriate care for PwM.

Methods: This study is a systematic analysis of national dementia care guidelines of the EU and EFTA countries. Using the discourse analysis model by Keller (2011), n=43 documents from n= 24 EU and n=3 EFTA countries were systematically screened for migration references via keyword and context analysis.

The content of the migration-related section was paraphrased, memos and comments were added and the individual text passages were coded.

Results: 27 of the 35 EU- and EFTA countries have national care guidelines for people with dementia and twelve refer to migration. Norway, Sweden, and Northern Ireland refer to this topic in detail. The focus of
the migration-related guidelines is on early detection and dementia diagnosis. The main message is that standardized diagnostic tools such as the Mini-Mental State Examination are not suitable for linguistic minorities. Nine countries make recommendations for the care of PwM and dementia but only Norway, Sweden, and Denmark point to available healthcare services. A key recommendation is that the linguistic and cultural background of people should be considered when selecting diagnostic tests. Several countries refer to the validity of theRowland Universal Dementia Assessment Scale for PwM.

Conclusions: The topic of migration plays a subordinate role in the care guidelines of European countries. Almost all countries lack appropriate diagnostic tools and healthcare services for PwM. Consequently, PwM are a risk group for underdiagnosis and a lower level of care.

QOP3.5. Do medicines regulators adequately address the public health needs in Alzheimer's disease?

LASSEN Anders1, MORANT Anne1, MORANT Anne2, LASSEN Anders1
1Lundbeck, Valby, Denmark, 2Lundbeck, Copenhagen, Denmark

Regulatory agencies such as the US Food and Drug Administration (FDA), the European Medicines Agency (EMA), and the Japanese Pharmaceuticals and Medical Devices Agency (PMDA) play a central role in facilitating development and eventually the availability of new treatments to patients by partnering with sponsors to discuss and provide guidance for development of novel drugs.

The regulatory guidelines are highly valuable information sources for sponsors to understand the regulatory thinking on drug development within the given therapeutic area and provide a great starting point for dialogue between sponsors and regulators.

Unlike many other therapeutic areas, regulatory guidelines for the clinical development of drugs to treat Alzheimer’s disease (AD) are available from three agencies, i.e., FDA, EMA, and PMDA.

Harmonization of regulatory recommendations and requirements has an important impact on global drug development in AD and other disease areas, but an important question remains: Does the overall scope of the guidelines reflect the public health needs in Alzheimer’s disease?

The presentation will be based on our recently published review of the current US, EU and Japanese regulatory therapeutic development guidelines for AD,[1] the scope can be adjusted as needed to ensure coherence with other presentations included under the same overall topic:


QOP3.6. Assessing the effect of prescription rate of anticholinergic medications on cognitive decline

ZAFEIRIDI Evi, MCMICHAEL Alan, MCGUINNESS Bernadette
Queen's University Belfast, Belfast, United Kingdom

A dementia diagnosis is often associated with increased medication use. Some of these medications which are routinely prescribed to people with dementia, including antipsychotics and antidepressants, have anticholinergic properties which block the neurotransmitter acetylcholine. The long-term use of anticholinergic drugs is likely to contribute to cognitive decline and to increase the risk of a dementia diagnosis. This retrospective study analyses data for over 8,000 older adults from the Northern Ireland Longitudinal Study of Ageing database to evaluate the effect of the anticholinergic drugs on cognitive skills. Demographic and medication data from older adults’ health assessment and a computer-assisted personal interview was matched with their performance on cognitive tasks, such the Mini Mental State Examination, the Montreal Cognitive Assessment and an animal recall task. Results are discussed in terms of the effect of a high rate of anticholinergic medication use and the overall cognitive decline, as well as decline in specific cognitive skills.

QOP3.7. Risk factors for dementia: a retrospective study assessing predictors of dementia in Northern Ireland

ZAFEIRIDI Evi, MCMICHAEL Alan, MCGUINNESS Bernadette
Queen's University Belfast, Belfast, United Kingdom

Several factors increase the likelihood of developing symptoms of dementia. Some of these factors are identified in midlife and late-life and they can be modifiable, such as smoking and physical exercise. These factors are likely to reduce the risk of receiving a dementia diagnosis in later life. This retrospective study analyses data from a large portion of the population in Northern Ireland that is collected by General Practitioners and is linked through the GP Intelligence Platform (GPIP) and the Honest Broker Service. This data will be cross-referenced with data from the Enhanced Prescribing Database that holds information about medication prescriptions. Over 25,000 people with dementia have been identified between 2010 and 2016 through prescriptions of dementia management medication, while the control group consists of people without dementia. Results are discussed in terms of the risk of receiving a dementia diagnosis based on modifiable and non-modifiable risk factors, including comorbidities and lifestyle, such as smoking.
QOP3.8. The association of depression with structural brain markers and cognitive impairment: The Maastricht Study

GERAETS Anouk, SCHRAM Miranda, JANSEN Jacobus, KOSTER Annemarie, DAGNELIE Pieter, VAN GREEVENBROEK Marleen, STEHOUWER Coen, VERHEY Frans, KÖHLER Sebastian
Maastricht University Medical Center+, Maastricht, Netherlands

Background: The risk of dementia is increased for older people with major depressive disorder (MDD). The underlying etiology remains unclear. Clinical studies suggest that depression is related to brain atrophy and cerebral small vessel disease (CSVD), which are themselves related to cognition. We studied the associations between depression, structural brain markers and cognitive impairment in a general population aged between 40 and 75 years.

Method: We used cross-sectional data from the Maastricht Study (n=4,734; mean age 59.1±8.6 years, 50.2% women), which, by design, oversampled participants with type 2 diabetes. A current episode of MDD (n=151) was assessed by the Mini-International Neuropsychiatric Interview. Volumes of cerebral spinal fluid, white matter, grey matter and white matter hyperintensities, presence of lacunar infarcts and cerebral microbleeds, and total CSVD burden were assessed by 3 Tesla MRI. Multiple linear and logistic regression analyses tested the associations between MDD, brain markers and cognitive functioning in memory, information processing speed, and executive functioning & attention, and presence of cognitive impairment. Structural equation modeling was used to test mediation.

Results: In fully adjusted models, MDD was associated with lower scores in information processing speed (mean difference=-0.18[-0.28;-0.08]), executive functioning & attention (mean difference=-0.13[-0.25;-0.02]), and with higher odds of cognitive impairment (OR=1.60[1.06;2.40]). MDD was associated with CSVD in participants without type 2 diabetes (OR=1.65[1.06;2.56]), but CSVD or other markers of brain atrophy or CSVD did not mediate the association with cognitive functioning.

Conclusion: MDD is associated with cognitive impairment, worse information processing speed and executive functioning & attention. CSVD burden was higher in depressed participants without type 2 diabetes, but did not explain their worse cognitive profile. Longitudinal studies are needed to examine the role of structural brain damage in the development of cognitive impairment and dementia in depression.

QOP3.9. Traumatic brain injury, childhood adversity and the long-term effects on adult outcomes and dementia: a Dementias Platform UK (DPUK) multi-cohort study

BAUERMEISTER Sarah, GALLACHER John, GEORGHE Delia
University of Oxford and Dementias Platform UK (DPUK), Oxford, United Kingdom

The consequences of traumatic brain injuries (TBI) on long-term cognitive and neurobiological outcomes is poorly understood however, there is support for evidence which suggests those who have experienced a TBI in younger adulthood experience diminished cognitive reserve which may accelerate cognitive deficits, premature cognitive decline and dementia risk (Wood, 2017). Furthermore, individuals who have experienced traumatic emotional experiences in younger years, also known as adverse childhood experiences (ACEs), a broad construct encompassing overall extreme difficulties and adverse experiences during childhood such as sexual, physical and emotional abuse, deprivation, and family dysfunction (e.g., McLaughlin, 2016) are at risk of adult depression (Liu, 2017), lower adult life satisfaction (Hughes et al., 2016) and dementia (Radford et al., 2017). We conducted a cross-platform cross-cohort investigation interrogating three Dementias Platform UK (DPUK) population cohorts to investigate self-report retrospective TBIs and ACEs as determinants of adult outcomes including cognition and dementia. Results suggest that there are significant negative effects of early adversity on longitudinal mental health and cognition.

QOP3.10. With Alzheimer's in the Alps

VERSCHRAEGEN Jurn
Expertisecentrum Dementie Vlaanderen, Mechelen, Belgium

Most reports on early onset dementia (EOD) deal with deficits and deterioration. Yet, subjects hit by EOD seek for ways to deal with the condition. Together with their families, they try to find meaning, challenges and new balances despite the condition. In September 2020, four people with Young Dementia and their buddies/partners stepped into the Italian Alps, under the guidance of the 'Brain Adventure Team', a group of enthusiastic doctors and care workers who will experience an adventurous holiday together with people with EOD. During the hike the goal was to enjoy nature but also to make a travel guide which could then be used to give other groups of people with EOD the opportunity to make a accompanied tour in the Alps. The travel guide is unique because it was written together with people with EOD: their ideas, their warnings, the dangers during the trip, the altitude differences, the meals, the importance of a good night's sleep, but also how to prepare for such an adventure are described. What is very special is that in the travel guide we named 'With Alzheimer's in the Alps', in addition to the whole route, a special connection was made with the local hotel managers so that they are well prepared if groups of people with dementia come to stay in the future. The outcome of this adventure demonstrated that people with EOD are still capable of great performances if they are surrounded by a supportive and stimulating environment. In his
Frontotemporal dementia is characterized by profound changes in behaviour and personality that often onset at young age. It is known that FTD causes unique challenges for the caregivers involved as they often have to cope with socially awkward, disinhibited or compulsive behaviour in their relative. As a result, caregivers of persons with FTD have specific support needs and often do not recognize themselves in the currently available support services, as most are aimed at caregivers of persons with Alzheimer’s dementia. Therefore, we aim to tailor the evidence-based self-management intervention “Partner in Balance” (PIB) to the needs of FTD caregivers, in close collaboration with the target group.

Methods: To tailor the PIB-intervention to the needs of FTD-caregivers, we used the Medical Research Council Framework as a guideline and (1) analysed the results of previously conducted feasibility trials on PIB, (2) organized three focus group discussions with 24 caregivers of persons with FTD, and (3) consulted field experts, healthcare professionals and FTD caregivers during the developmental process.

Results: Based on this iterative process twelve new modules for FTD caregivers were developed. These modules focus on themes such as: acceptance, coping strategies, social support, family life, sexuality and intimacy, heredity aspects, and coping with language or behavioural changes. Each module contains (1) a video vignette in which FTD caregivers share their experiences, (2) psychoeducation with narrative stories and tips from FTD caregivers, (3) a self-reflection assignment, and (4) a step-by-step change plan. Currently, a trial is conducted that includes 15 caregivers to examine the feasibility of these newly developed modules by means of qualitative and quantitative measures.

@AE2020: At the upcoming Alzheimer Europe conference, we hope to emphasize the importance of appropriate support for FTD caregivers by presenting the first results of this feasibility trial in the context of the iterative development process.
QOP3.13. Representing a patient’s dementia pathology using an auto-generated Dementia Biomarkers Report

MSAYIB Yunus, BUCKLEY Chris
GE Healthcare, Amersham, United Kingdom

Background: Current research accepts that a combination of imaging biomarkers can provide refinement in the assessment of risk of clinical progression for patients experiencing cognitive impairment. Imaging biomarkers of dementias obtained using PET and MRI are playing an increasingly important role in dementia research, although practical clinical application of imaging biomarkers to individual patients has yet to see wide adoption. In this work we present an automated analytics solution, the Dementia Biomarkers Report (DBR) app, which is intended as a diagnostic aid for the clinical workup of individuals manifesting symptoms of preclinical dementia.

Methods: The DBR app generates an individualised biomarker report of dementia pathology, referred to as a Dementia Biomarkers Report. The patient’s DBR is comprised of biomarker data automatically extracted from the patient’s PET and MRI scans using neuroimage analysis tools. The DBR app synthesises the biomarker values into a short PDF report, which reports an age-matched classification of biomarker normality or abnormality using A/T/N notation.

Results: The first page of the DBR enumerates imaging biomarkers that have associations with different dementia pathologies. A “+” sign indicates an abnormal biomarker value, defined as being in the 5% tail of an age-matched distribution of cognitively normal (CN) subjects (derived from fitting a distribution to 314 PET-MR datasets). The second page shows how the patient’s biomarker values compare to CN subjects across an age range from 50-90Y. The third page serves as a visual quality control check of the automated analyses. Case study: subject had amnestic MCI and transitioned to AD 2.5Y from baseline imaging date. Their DBR – obtained at baseline – reported presence of Alzheimer’s pathology (A+), with evidence of hippocampal neurodegeneration (N+), suggesting the progressive degeneration phase had started.

Conclusion: We have proposed the Dementia Biomarkers Report as an aid in the differential diagnosis of dementia.

QOP4. Quick oral presentations – People

QOP4.1. “Jumping into the research”: Insights from the SPEAR study into motivations and expectations of participation in Alzheimer’s disease research

BRENMAN Natassia, MILNE Richard
University of Cambridge, United Kingdom

Across contemporary scientific contexts, ‘participation’ has come to be known in terms of problems; of how it can be done better and why people are motivated (or not) to participate (Kelty 2020). Research participation in longitudinal Alzheimer’s disease research presents a unique set of problems, possibilities, and experiences, which have so far received less attention. We explored these from the perspective of research participants themselves, through the Study of Participant Experience of Alzheimer’s disease Research (SPEAR), a mixed-methods sub study of the Innovative Medicines Initiative European Prevention of Alzheimer’s Dementia (EPAD) project. In this presentation, we present key findings from SPEAR, focussing particularly on the question of why people are motivated to participate.

We will first draw on data from the quantitative arm of the study, a questionnaire survey completed by 101 participants and 7 study partners from 4 EPAD sites across the UK. Then, we relate this to findings from the qualitative work: in-depth interviews with 25 EPAD participants, and observations of study visits from the same 4 sites.

We will discuss how helping others, or ‘altruism’, was the key reason that people initially became involved in EPAD, but also how, over time, other important reasons had emerged, such as being “kept an eye on” or valued by researchers. People also discussed different motivations as they considered taking part in a clinical trial – as one participant said: “if this was a possibility to counteract [future] symptoms, we would welcome that, but the purpose of jumping into the research was much more altruistic”. As such, the SPEAR study highlights how participants’ changing life situations were crucial to how they became involved, continued to participate, and thought about future trial participation.

QOP4.2. Moved to Oral

QOP4.3. Predictors of caregiver depressiveness in dementia: Results of the Bavarian Dementia Survey (BayDem)

KÜRTEN Lara1, DIETZEL Nikolas1, KOLOMINSKY-RABAS Peter1, GRÄSSEL Elmar2
1Interdisciplinary Center for Health Technology Assessment (HTA) and Public Health (IZPH), Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany. 2Center for Health Services Research in Medicine, Department of Psychiatry and Psychotherapy, University Hospital Erlangen, Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany
Background: The majority of people with dementia (pwd) are cared for at home by their relatives. These informal caregivers form a risk group of depressiveness.

Research question: What are predictors of depressiveness in informal caregivers?

Methods: BayDem is a multi-center, longitudinal study that was conducted at three different sites in Bavaria, Germany. Participants were pwd (according to ICD-10) and their informal caregivers. Data was collected by standardized face-to-face interviews in collaboration with local players. Caregiver depressiveness was measured using the WHO-5 Well-Being Index. Multiple regression was used in order to identify predictors of depressiveness.

Results: In total, the data of 300 informal caregivers was analyzed. Caregivers were above-average depressed as compared to a German representative sample of similar age. Behavioral and psychological symptoms of dementia (BPSD, assessed with the Neuropsychiatric Inventory, NPI) and the social integration of caregivers (assessed with the Lubben Social Network Scale, LSNS) were among the main predictors of depressiveness.

Discussion: This German population study was able to illustrate that high BPSD scores and low social inclusion in a network are risk factors for high levels of caregiver depressiveness. The data confirms findings from international studies.

Practical implications: To treat BPSD, psychosocial interventions such as the MAKS-therapy have proven effective. Additionally, social inclusion can be fostered through neighborhood projects such as multi-generation houses, dementia cafés or support groups.

Funding notice: digiDEM Bayern is funded by the Bavarian Ministry of Health and Care as part of BAYERN DIGITAL II (funding code: G42d-G8300-2017/1606-83).

QOP4.4. Perceptions of community services by dementia informal caregivers in Greece: are family bonds important?

KOUKOULI Sofia¹, KALAITZAKI Argyroula¹, PANAGIOTAKIS Symeon², MARKAKIS Georgios³, WERNER Perla⁴, TZIRAKI Chariklia⁵

¹Hellenic Mediterranean University, Heraklion, Greece, ²Internal Medicine Department, Medical School, University of Crete, Crete, Heraklion, Greece, ³Department of Social Work, School of Health and Social Welfare, Hellenic Mediterranean University, Crete, Heraklion, Greece, ⁴Department of Community Mental Health, University of Haifa, Haifa, Israel, ⁵Research and Evaluation Department, Community Club of Elders, Research Department, Community Elders Club (MELABEV), Jerusalem, Israel

Aim: This cross-sectional study investigated perceptions of health and social care services and their correlates by informal caregivers of community-dwelling persons with dementia (PwD), using the theoretical framework of the Behavioral Model of Healthcare Utilization.

Methods: A purposive sampling technique identified 118 informal caregivers of PwD (78.8% female, mean age = 58.9 years) with whom face-to-face interviews were conducted via a structured questionnaire.

Results: Factor analysis identified three ‘Perceptions of Services’ subscales: ‘Availability and Adequacy of Services’ (AAS), ‘Physicians’ Competence’ (COMP), and ‘Professionals’ Behaviour’ (PB). Multiple Regression Analysis showed that both predisposing factors (gender, employment, familism) and enabling/impeding factors (caregiving impedes work, quality of life aspects -environment and social relationships- information about dementia) were significant correlates of the AAS and COMP subscales. Familism was negatively correlated with the AAS subscale. PwD’s perceived physical and behavioral declined functioning (KATZ) was related to worse perceptions regarding professionals’ behavior (PB) toward the PwD.

Conclusion: The study provided insight on the factors associated with caregivers’ perceptions of health and social care community services, which, in turn, may direct interventions to increase PwD and caregivers’ awareness on the use of the services and therefore, delay potential institutionalisation.

QOP4.5. Withdrawn

QOP4.6. Experiences with online Alzheimer Cafes

CONIJN Sandra

Alzheimer Nederland, amersfoort, Netherlands

Alzheimer Nederland has 250 Alzheimer Cafés. The Alzheimer Cafés are an easy approachable way for people with dementia, caregivers an healthcare professionals to meet each other. The corona crisis forced the Alzheimer Cafes to close. This resulted into a loss of contact with others and a lack of sharing information and experiences about dementia for the visitors.

To provide an alternative to the visitors of the Alzheimer Cafes, the regional departments of Alzheimer Nederland transformed the Alzheimer Café into an online cafe. The regional departments used different ways to set up this online Alzheimer Café to continue the contact with the visitors and to support them during the time in which it is most needed. An online Alzheimer Café is an initiative that might be continued after the corona crisis. We are currently examining the possibilities to continue the online Alzheimer Cafés, not as a replacement but as an addition. In October we would like to share our experiences with the online Alzheimer Cafes and share the experiences of the visitors and the different variants.
**QOP4.7. Behavioural and psychological symptoms in community dwelling people with dementia: Bavarian Dementia Survey**

MEUER Sebastian¹, KOLOMINSKY-RABAS Peter¹, GRÄSEL Elmar²

¹Interdisciplinary Center for Health Technology Assessment (HTA) and Public Health (IZPH), Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium 'Digital Dementia Registry Bavaria – digiDEM Bayern', Erlangen, Germany; ²Center for Health Services Research in Medicine, Department of Psychiatry and Psychotherapy, University Hospital Erlangen, Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium 'Digital Dementia Registry Bavaria – digiDEM Bayern', Erlangen, Germany

Background: Behavioural and psychological symptoms of dementia (BPSD) are common in people with dementia (pwd). BPSD are associated with caregiver distress. Especially BPSD in the nursing home setting is well known, whereas little information is available for BPSD in community-dwelling pwd.

Method: BayDem is a multi-center longitudinal study that was conducted at three locations (Dachau, Erlangen, Kronach) in Bavaria. Participants were pwd (according to ICD-10) and their informal caregiver. Data was collected by standardized face-to-face interviews. The Neuropsychiatric Inventory was widely used for BPSD evaluation and caregiver burden.

Results: In total 330 pwd could be evaluated. Merely 6% show none BPSD. The other pwd show symptoms of varying severity. The most frequent symptoms reported were depression, aggression, irritability and apathy. There is a strong positive correlation ($r = .869, p <.001$) between the recorded stress experienced by caregivers and the severity of BPSD.

Conclusion: Our results demonstrate the impact of BPSD on the burden of care for family caregivers in community dwelling. Furthermore, BPSD play an important role in long-term outcome as well as health economics as BPSD are the most common cause for shift into institutionalized care. In order to reduce BPSD, suitable interventions for the home environment should established. Non-pharmacological interventions can be the first choice of therapy for community-dwelling pwd.

Funding: The Bavarian Ministry of Health and Care funded BayDem (funding code: G42b-G8092.9-2014/10-7).

**QOP4.8. France Alzheimer's Institute**

FRASCA Guillaume

France Alzheimer and related diseases, Paris, France

In order to meet families’ need for information and support, the training of family caregivers and volunteers of our local branches has been one of the core missions of France Alzheimer since its creation in 1985. Along with the evolution of the needs and of the sanitary, social and medical context, the Association has gradually improved its offer by providing training courses to health-care professionals. It is indeed essential that families can rely on professionals trained to deal with the specific symptoms of the disease. As an approved training organisation since 1991, France Alzheimer decided in 2019 to develop the Association’s brand and this global approach dedicated to the people we daily assist. This is how France Alzheimer’s Institute is born.

The trainings provided by the Institute are part of the patient’s healthcare pathway. They are meant to improve care at various stages of the disease, from the initial diagnosis to end-of-life palliative care. They are aimed at care and home care professionals, as well as health and social institutions managers, eager to provide adequate training for their staff.

The institute aims to:
- enhance care;
- maintain a trusting relationship between professionals and families;
- change the attitudes towards the disease;
- facilitate the well-being of healthcare staff and patients;
- fight against Alzheimer’s and related diseases in the long term.

The educational approach is interactive, lively and adapts to the participants’ real needs. It is designed to enable them to be proactive in their daily work. This expertise is the fruit of France Alzheimer’s field experience, as well as of clinician trainers’ scientific experience.

The Institute’s ambition is to strengthen the trusting relationship between patients and healthcare and support professionals. This is necessary in order to guarantee everyone’s well-being and change our attitudes towards the disease.

**QOP4.9. Voices of the community: spotlight on the lived experiences of agitation**

MICHAEL Mary, TOLMACHOV Vasily

Otsuka, Princeton, United States

Objective: To better understand the challenges, opportunities, and “lived experience” of informal care partners and professional caregivers who provide care to people experiencing agitation due to Alzheimer’s disease.
Background: Despite the notable progress that the Alzheimer’s community has made in providing resources and support for care partners of people living with Alzheimer’s, there has been inadequate attention given to the unique needs care partners and professional caregivers confront when providing care to people experiencing agitation. This shortcoming hurts care partners and people experiencing agitation. Agitation presents multiple challenges for care partners, including verbal and physical aggression, and even unwanted sexual advances. These symptoms can place a serious burden on care partners, with research pointing to an increased burden for care partners of people with agitation, compared to people with Alzheimer’s who do not experience agitation.

But before support, resources, and education can be created, it is vital to understand the specific and unique needs of care partners and caregivers in providing care to people experiencing agitation.

Methodology: To fill this knowledge gap, we undertook both qualitative and quantitative research, including: one-on-one interviews with care partners who identified as caring for a person with agitation; one-on-one interviews with advocacy organization leadership identified as working closely with care partners and people with agitation; a review of a company intranet discussion board of professional caregivers who self-identified as caring for clients with agitation; and a review of social listening data from online platforms.

Results: Results will describe the unique, multifaceted challenges care partners and caregivers face when caring for people experiencing agitation.

Conclusion: The research suggests three areas where care partners and caregivers need the most support:

1. Noticing the signs and symptoms of agitation
2. Getting a diagnosis
3. Finding resources that work in the absence of adequate agitation-specific materials

QOP4.10. Withdrawn

QOP4.11. Occupational therapy for older people with dementia and caregivers (COTID) within the multicultural context

BAKKER Kim¹, GRAFF Maud¹, ROETS Lieve¹, THIJSSEN Marjolein²
¹Radboud University Medical Center, Department of Rehabilitation and Radboudumc Alzheimercentre, Nijmegen, Netherlands, ²Radboudumc, IQ healthcare, Nijmegen, Netherlands

The COTID program is an effective community-based occupational therapy program for elderly persons with dementia and their caregivers at home. The program was originally developed in 1998 and was updated in 2010. Within this program, elderly people with dementia and their informal caregivers are assisted in carrying out meaningful activities with the aim to improve the self-esteem and personal effectiveness of the person with dementia and to increase the problem solving and competence of the informal carer.

COTID trained occupational therapists have the impression that people from minority ethnic groups with dementia often do not receive occupational therapy and they experience dilemmas during treatment. These therapists asked whether the COTID can receive a supplement for adaptation of the program aimed at elderly people with dementia from various minority ethnic groups. Initially with a Moroccan migration background and then also with a Turkish and a Chinese migration background. In June 2019 a study commenced with the aim to gain insight into whether and which adjustments are needed to the (application of) COTID program in order to be able to provide adequate home-based occupational therapy for Moroccan elderly people and their informal caregivers.

The first two steps of action research is being performed in the first year of research. In four iterative cycles an understanding of the perspectives, experiences, needs and recommendations for change of COTID trained occupational therapists, occupational therapists with a Moroccan migration background and Moroccan elderly people with dementia and their caregivers will be obtained by performing individual interviews, focus groups and a questionnaire.

During the presentation the first results and the progress of the research will be presented.

QOP4.12. Creating a Research Agenda with people with dementia and carers

BLOK Hester
Alzheimer Nederland, Amersfoort, Netherlands

Goal: Alzheimer Nederland wants to fund research that directly influences the situation of people with dementia (pwd) and their caregivers. That is why our new research agenda is based on their experiences. Our goal was to put pwd and caregivers at the helm of the process towards this agenda.

Method: We defined several steps to achieve a set of research priorities. At each step, informal caregivers and pwd gave their input, both in face-to-face meetings and via our online panel (2000 caregivers of pwd).

Results: There were various ways in which we asked for input:

1. In two meetings informal caregivers discussed, together and with other stakeholders, the major bottlenecks in their care for someone with dementia (140 participants).
2. In four group discussions with pwd, we discussed what they consider important (40 participants). We analyzed the input from 1. and 2. with the help of informal caregivers, scientists and other stakeholders and converted that into 11 concrete goals.

3. We asked members of our online panel to rate these goals, if possible together with the pwd (n = 639, 58 together with pwd). From this step, we were able to prioritize the 11 goals.

Conclusion: We have been able to put pwd and caregivers at the helm of this process. Now there is a research agenda in which they recognize themselves and in which their needs are reflected. Now we can fund research on the top three priorities that have emerged:

- Prevent overload of caregivers
- Search for activities for pwd, at home and in the nursing home
- Personalized care and attention in the nursing home

When funding research, we use guiding principles to ensure that the research has maximum impact. In this way we enable better care and support for people with dementia and informal caregivers.

**QOP5. Quick oral presentations – Policy**

**QOP5.1. “Dementia friendly spots” a network providing information and support in local communities**

L. ZLOBEC Štefanija, KRIVEC David, BASTARDA Maša, KEČKEŠ Polona
Spominčica - Alzheimer Slovenija, Ljubljana, Slovenia

Dementia Friendly Spots (DFS) is a national awareness raising programme, they help create a dementia-friendly environment by encouraging and ensuring greater inclusion, acceptance and safety of people with dementia and their carers in society. Organizations in the DFS network also provide friendly and accessible use of their services for persons with dementia in local communities

The first DFS was opened at the Human Rights Ombudsman office after the training of employees. The opening was covered by national media. Member of EWGPD presented his life with dementia and stressed the importance of building dementia inclusive society.

Since, there has been a growing interest in DFS from organizations all around the country. The training programmes for covers the topics about dementia and first signs, communication with persons with dementia, importance of timely diagnosis, post diagnostic support and rights of PwD. Then, an official opening with culture programme is organized, where all important stakeholders from local community are present and is covered by media. The organization is presented with a DFS sticker, a certificate and put on web map. Activities are evaluated, and trainings are periodically renewed. DFS network consists of more than 200 different organizations: Nursing homes, Intergenerational and Family Centres, Health Centres, Pharmacies, Libraries, the Police, Social Work Centres, and Red Cross organizations. The Ministry of Social Affairs, Ministry of Health, Ministry of the Interior, the Ministry of Defense and the Social Chamber of Slovenia, the National Institute of Public Health, and the Faculty of Social Work also joined the DFS network.

Persons who visited DFS most often wanted information about the disease, the first signs of dementia and existing forms of help. They also often needed help in managing critical situations, resolving problems, congestion, helplessness, and problems in caring for a person with dementia.

**QOP5.2. Reviewing the definition of multimorbidity and comorbidity in dementia care**

DUNN Rosie, CLAYTON Ellie, WOLVERSON Emma, HILTON Andrea, PRICE Elizabeth
University of Hull, Hull, United Kingdom

There are two common terms used in the dementia care literature to describe people living with multiple health conditions; ‘comorbidity’ and ‘multimorbidity’. However, these terms lack a standardised definition and conceptualisations differ between practitioners and researchers. In this presentation we review the definitions of multimorbidity and comorbidity and share a standardised definition which we hope will inform future research and clinical practice as well as raise awareness of the importance of the language we use in dementia care.

We systematically searched for articles containing definitions of multimorbidity and comorbidity in the context of dementia care. We developed an operational framework of multimorbidity from the retrieved articles. Abstracts and titles of 4261 articles were screened from five databases: MEDLINE, PsycINFO, PsychArticles, Academic Search Premier and CINAHL. 27 articles were included for review. A narrative synthesis revealed four key findings; there was considerable overlap between definitions and concepts of comorbidity and multimorbidity; definitions were overly medicalised and only focussed on physical health conditions; when a comorbidity definition was used, the chosen index disease was dependent on the researchers interest and the majority of articles cited definitions from non-dementia research.
This presentation will review the definitions of comorbidity and multimorbidity in the context of dementia care. We demonstrate that although the two terms are independent of one another they are used interchangeably. There was also an indication that definitions used within dementia care were not specifically linked to dementia. We will present an operational framework that compiles a comprehensive definition of multimorbidity within dementia care, taking into account dementia severity, the role of carer and healthcare professionals.

QOP5.3. The impact of advance directives in Portugal

ZINCKE DOS REIS Maria Do Rosário
Alzheimer Portugal, Lisbon, Portugal

From 2014 till the end of March, only 30 626 people, in Portugal, registered their advance directives at RENTEV (the national digital platform created to register living wills and health care proxies). The Portuguese population is of about 10 million people. Why only such a small percentage of people felt motivated to write a living will or to appoint a health care proxy? Possible reasons: lack of information and awareness; misperception with euthanasia; difficulties in understanding and fulfilling the form; lack of concern about the future; paternalistic approach from doctors, nurses and even patients: “the doctor will know what will be the best for me.”

Making an advance directive is an exercise of autonomy. It is about making our own choices and decisions instead of letting the others decide about us. “Nothing about us without us”. It will avoid uncertainty and feelings of guilty among our family and friends if they are asked to participate in difficult decisions about our health in a moment that we lost our autonomy to do it.

Is the Autonomy a not strong enough ethical principle? Don’t we need to strengthen the moral intimacy between doctor and patient to make them feel more comfortable to discuss end of life issues? Would discussing advance directives in the framework of advance care planning help to raise awareness?

The Portuguese Association of Bioethics submitted a proposal to the Parliament to change the Act of the Parliament nº 25/2012 (regulating the Advance Directives), in order to include a rule stating that every adult at the admission in a public or private hospital shall be informed about the right of subscribing an advance directive.

These are some issues around the impact of advance directives we would like to develop at the oral presentation.

QOP5.4. The National Strategy of Alzheimer Nederland: how did we convince our minister of health to give priority to dementia?

MEERVELD Julie, De BOER Anne
Alzheimer Nederland, Amersfoort, Netherlands

The National Dementia strategy 2021-2030 in the Netherlands: how did we convince our minister of health to give priority to dementia?

Alzheimer Nederland created a national strategy for the Netherlands with our vision: a future without dementia and an improved quality of life for everyone who is dealing with dementia. We use this strategy to make our own responsibilities explicit but we also underline the urgency of doing it together. Together with healthcare insurances, together with the government, together with the municipalities and of course based on the voice and needs of people with dementia and their caregivers. The strategy is concretized into objectives, goals, strategies and measures and it consists of 4 main subjects, namely Research, Support and Care, Prevention, and a Dementia Friendly Society.

Our strategy inspired the ministry of Health, Welfare and Sport to create a similar strategy for the Netherlands that is based on our mission. We work closely together to realize the best results possible. In our presentation we will further explain our strategy and elaborate on the actions we took to achieve an influence of the strategy on a national policy level.

QOP5.5. Costs incurred by people with pre-dementia or dementia

LANDEIRO Filipa, NYE Elsbeth, GHINAI Isaac, MUGHAL Seher, WILLIAMS Harriet, BEDDOWS Nicola, WACE Helena, BENNETT Christopher, MCEWAN Kevin, HANDELS Ron, GRAY Alastair
United Kingdom

Background: Disease progression in dementia is typically associated with increasing costs. Despite being large and growing, these are still difficult to quantify.

Aim: To identify estimates of costs incurred by people with pre-dementia or dementia.

Methods: We conducted a systematic review of the literature to find estimates of cost incurred by PWD in each stage of the disease, by searching for relevant studies in electronic databases between January 2000 and May 2017.

All extracted costs were converted to USD at 2016 prices. Where studies reported costs for different disease stages, and clearly reported the setting of the study, ratios of costs in the mild cognitive impairment (MCI), moderate and severe stages compared to the mild stage were calculated.
Results: We identified 121 studies reporting costs for MCI, mild, moderate or severe dementia. Limited data was found for direct carer costs (such as healthcare use due to the caregiving role) and productivity losses for both PWD and their carers.

In comparison to mild dementia costs, medical costs were not found to be significantly different between disease stages or between settings. Non-medical costs, increased for PWD living in the community as disease severity worsened; in an institutional setting, these costs were equal for all disease stages. Studies conducted in mixed settings showed an increase in total costs as the disease progresses driven by the increase in number of hours of informal care and the transition from community to institutional care.

Discussion: The important role of the carer in this disease is reflected in the increasing costs observed in the community and mixed settings as disease progresses. Nevertheless, not all carer related costs have been captured by most studies.

At an institutional level, the lack of granularity in terms of hours of care might explain the no change in costs as disease progresses.

**QOP5.6. Brain Health Scotland: a national initiative to reduce incident dementia**

RITCHIE Craig¹, SIMMONS Henry², BORTHWICK Anna³

¹University of Edinburgh, Edinburgh, United Kingdom, ²Alzheimer Scotland, Glasgow, United Kingdom, ³Brain Health Scotland, Edinburgh, United Kingdom

It is known that the diseases, which lead to dementia, start (at least) in midlife. The onset of disease is driven by many risk factors that are both fixed (family history and genetics) and modifiable (e.g. lifestyle) as well as interacting with other medical and mental health comorbidities (e.g. diabetes and depression).

The application of the research evidence base into clinical practice and public campaigns though has been piecemeal within most settings and lacking leadership and coordination. To address this the Scottish Government in April 2020 launched Brain Health Scotland within their Programme for Government. Brain Health Scotland coordinates existing national activities and will develop new specific ones in three integrated domains: [1] Health Informatics, [2] Research and [3] Clinical Practice and Public Health.

Brain Health Scotland will achieve its core objective of reducing incident dementia through two main avenues. Firstly, the establishment of Brain Health Services that will provide individuals with risk profiling, early disease detection and implementation of Personalised Prevention Plans. Secondly a series of public health initiatives will be undertaken across the life course focussed on developing and maintaining brain health. These will involve education from school years onwards, lifestyle messaging and management of comorbidities with various targets for these messages and stakeholders in delivering them. Brain Health Scotland will produce a Brain Health Strategy for Scotland as well as a Scottish Brain Health and Dementia Research Strategy.

Brain Health Scotland builds on and has continued to develop the Scottish Dementia Informatics Partnership (which is overseeing the development and roll out of the Scottish Brain Health Register), the Scottish Dementia Research Consortium and is actively putting in place the Scottish Early Alzheimer's Disease Detection (SEADD) Programme. These elements and summary of their achievements will be presented in the context of the broader Brain Health Scotland organisation.

**QOP5.7. The Scottish Brain Health Register**

KILLIN Lewis¹, RITCHIE Craig², GREGORY Sarah¹, DOULL Laura¹, PENNINGTON Catherine³

¹Edinburgh Dementia Prevention, Edinburgh, United Kingdom, ²Brain Health Scotland, Edinburgh, United Kingdom, ³NHS Lothian, Edinburgh, United Kingdom

The Scottish Brain Health Register (SBHR) is a database of people living with, or at risk from, dementia in Scotland. It serves two purposes: to connect people to research opportunities, and as a regularly updated, well-characterised population cohort.

SBHR is open to all members of the public interested in research, but is designed specifically for use in the clinical care pathway. Registration to SBHR entails consent to access an individual's demographic and medical data, to ensure that researchers can contact that individual about research opportunities and with sufficient medical prescreening to ensure they are offered appropriate opportunities. Effective prescreening facilitates recruitment into studies and the rate of discovery.

Critically, SBHR also asks that an individual's data be uploaded to its servers and made available for secondary analysis by members of the research community, including partners from industry, academia and the third sector.

If an individual participates in a research study, a subset of the data generated about them also enters their SBHR profile. The studies that recruit from – and by implication generate data for – SBHR are subject to review from local Portfolio Committees, who ensure that research opportunities are balanced and proportionate its registrants, and that data sharing is raised with investigators.

The SBHR+ programme applies this data sharing principle within Brain Health Clinics, and aims to bridge the current gap in practice between clinical care and research participation. Specifically, by inviting a Memory Clinic population to take part in SBHR+ research protocols that are not available under standard
healthcare practice (e.g., APOE analysis, CSF sampling, digital neuropsychology), clinicians can generate and have access to more detailed data that may impact their patient’s standard of care, formulate personalised prevention plans and build a national risk algorithm. SBHR+ data will ultimately then have significant use for disease modelling purposes.

QOP5.8. From plan to impact III, progress towards the WHO Global action plan on dementia

LYNCH Chris
Alzheimer's Disease International, London, United Kingdom

Background: At the World Health Assembly 2017, the World Health Organization launched the Global action plan on the public health response to dementia 2017-2025. Alzheimer's Disease International (ADI) monitors progress towards the action areas / targets of the Global plan and in June 2020 will publish “From plan to impact III”, to coincide with the first official reporting cycle for the plan.

Method: ADI continuously gathers information and updates relating to the 7 action areas of the Global action plan through our network of over 100 member associations and federations globally, plus our contacts and partners in research, science, health and care, people living with dementia and carers. A specific analysis of progress towards the key goal of developing national dementia plans or strategies is a focal point of the research.

Result: Despite positive progress in 2019 with the introduction of dementia plans in Canada and Spain, and with up to 30 plans reportedly in development, there are still only 35 national plans in existence. This puts immense pressure on meeting the key goal in the Global action plan, which targets 75% (146) of Member States to have developed a plan by 2025. This equates to the need for over 26 new plans every year up until 2025.

Conclusion: Progress is being made across all 7 action areas of the Global action plan on dementia and updates are scheduled to the Global Dementia Observatory (GDO), however ADI, working with WHO and our partners, will continue to focus attention on governments across the world to take action, to develop robust and well funded national plans and to monitor their progress.

QOP5.9. Family carers’ preferences for psychosocial supports: informing policy using nominal group technique

TEAHAN Áine1, CARNEY Patricia2, CAHILL Suzanne3, O’SHEA Eamon1
1Centre for Economic and Social Research on Dementia, NUI Galway, Galway, Ireland, 2Department of Public Health, Health Service Executive, Galway, Ireland, 3Dementia Services Information and Development Centre, St. James Hospital, Dublin, Ireland

Introduction: Family carers of people with dementia report significant personal and economic challenges. Despite family carers being crucial to the sustainability of long-term care systems for people with dementia, there is limited research on their preferences for psychosocial supports and services. This research aimed to identify challenges experienced by family carers and directly ascertain their preferences for psychosocial supports and services in addressing those challenges.

Method: Three modified Nominal Group Technique (NGT) workshops were conducted with 17 family carers of people with dementia in Ireland. To reflect the complexity of family caring, the NGT workshops were conducted in two stages, focusing separately on personal level and wider social domains. Following in-depth group discussions, family carers identified challenges associated with caring and individually ranked preferences for novel and pre-existing psychosocial services and supports in both domains. Data analysis included qualitative content analysis and summative ranking scoring.

Findings: Family carers’ preferences for personal level supports and services included day-care, long-break respite, short-break respite, family carer support groups and social activities. Preferences for wider social supports and services included a non-means-tested monetary carer’s allowance, legal recognition, carer’s support grant, monthly wage and community awareness programmes. Qualitative content analysis identified personal level challenges as: needing a break; isolation; and relationship changes. Wider social challenges included: finances; rights and entitlements; and stigma and awareness.

Conclusion: Given that any long-term care system for people with dementia will rely heavily on family carers, it is important that their preferences inform policy decisions. To reflect the diverse challenges posed by family caring, psychosocial approaches should include both personal and wider social supports, particularly enhanced day-care provision and non-means tested carer’s allowance. Increased investment in these supports would not only maintain family carers’ contributions to community care in dementia, but also facilitate social inclusion, social connectedness and economic sustainability.

QOP5.10. Information sources for informal caregivers in rural vs. urban areas: the Bavarian Dementia Survey (BayDem)

HOLM Kristina1, GRAESSEL Elmar2, KOLOMINSKY-RABAS Peter1
1Interdisciplinary Center for Health Technology Assessment (HTA) and Public Health (IZPH), Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany, 2Center for Health Services Research in Medicine, Department of Psychiatry and Psychotherapy, University Hospital Erlangen, Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium ‘Digital Dementia Registry Bavaria – digiDEM Bayern’, Erlangen, Germany

Background: Previously, little attention has been paid to informal caregivers of people with dementia (IC) regarding the ability to identify and understand dementia-related information. Generally, the internet
represents an important source of information for IC. To date, little consideration has been given to differences in the evaluation of several information sources among IC from rural and urban regions in Bavaria.

Method: BayDem is a multi-center, longitudinal study that was conducted at three different sites in Bavaria, Germany. Participants were people with dementia (according to ICD-10) and their IC. Information sources were rated by the IC using Likert Scales with the values unimportant (1) to very important (5). The assignment of the IC's residence to two rural and two urban regions was determined by the classification of the Federal Institute for Research on Building, Urban Affairs and Spatial Development in Germany. Data was analysed using Kruskal-Wallis tests for independent samples.

Results: In total 332 IC could be evaluated. There were significant differences in the importance of the information sources "television/radio" (χ²(3) = 18.39, p < .000), "family, friends and colleagues" (χ²(3) = 7.83, p < .050) and "pharmacy" (χ²(3) = 15.75, p < .001) between the IC from the four regions.

Conclusion: The information sources "television/radio", "family, friends & colleagues" and "pharmacy" have a different relevance for IC from rural and urban regions. Dementia-related information should therefore be adopted to rural or urban setting. Online information sources can expand the IC's information spectrum.

Funding: BayDem was funded by the Bavarian Ministry of Health and Care (funding code: G42b-G8092.9-2014/10-7).

QOP5.11. How do support providers assess the needs of informal caregivers of persons with dementia?

PASQUIER Noémie, PIHET Sandrine
HES-SO: University of Applied Sciences and Arts Western Switzerland, School of Health Sciences, Fribourg, Fribourg, Switzerland

Informal caregivers who support a person with dementia (IC-D) play an essential role in the health care system. Their intensive contribution puts them at high risk of negative consequences on their physical and psychological health but despite their significant unmet needs IC-D belatedly ask for support. Identifying IC-D needs is essential for a timely solicitation or referral to relevant support services and for the prevention of exhaustion. Research about how diverse support providers assess IC-D needs is scarce. Our project aimed to describe these practices in one region of Switzerland, from the perspectives of support providers and IC-D.

A first survey was completed by 63 professionals and volunteers involved in IC-D support with 10 questions about how they assess IC-D needs. A second survey was answered by 34 IC-D with eight questions about how support providers assess their needs.

Providers indicated dedicating on average 45 minutes (range: 5-120 minutes) to assess the needs of IC-D. Only 48% of providers reported being trained for needs assessment and only 30% used a systematic procedure, with 41% describing heterogeneous assessment procedures in their department. Among IC-D, 77% considered that they could easily find the support they needed, although many commented this required much effort. Most IC-D perceived interest for their needs among the majority of support providers, particularly those specialized in dementia. Some IC-D described procedures lacking individualization or support providers focusing too exclusively on the care receiver.

In a context of shortage in qualified health care personnel, increasing numbers of people with dementia, and growing pressures on informal caregivers, a more efficient assessment of IC-D needs is desirable. An online screening questionnaire could be completed autonomously by a large proportion of IC-D and could provide a systematic profile of current unmet needs relevant for IC-D and diverse support providers.

QOP5.12. An online tool to assess the needs of informal dementia caregivers and refer them to the relevant support services

PIHET Sandrine, PASQUIER Noémie
HES-SO: University of Applied Sciences and Arts Western Switzerland, School of Health Sciences, Fribourg, Fribourg, Switzerland

Despite their significant unmet needs, informal caregivers of persons with dementia (IC-D) often call late upon support, waiting to be exhausted or in a crisis situation. The reasons for this include IC-D difficulties in identifying their needs and finding the adequate support service. The project aims to develop an online platform to help them identify and prioritize their needs as well as find adequate support within the local network, in one region of Switzerland.

In this project, we first developed 46 items covering the diversity of IC-D needs based on eight questionnaires with good content validity identified within a systematic psychometric review. Then we assessed the relevance and exhaustiveness of the developed items from the perspective of 42 support providers and 28 IC-D using a survey, as well as clarity of items for IC-D. In addition, we identified optimal support services for each assessed need from the perspective of the 42 surveyed providers.
Poster presentations

PO1. Care approaches

PO1.1. Certification-D – testing and certifying products for people with dementia at the ARCK Living Lab in Krefeld, Germany

KRAH Katrin, SPANIER Helen
Alexian Research Centre, Krefeld, Germany

From 2018 to 2050, the number of people with Dementia will increase from 3.8 to 8.5 million in north west Europe (NWE). As stationary forms of care for people with dementia are not fit the need and most people prefer to stay in their familiar surroundings, more people will live at home in the future. This requires supporting through technical products. People with dementia and their care givers often do not know or trust existing products.

The interreg project “Certification-D” is set up for three years and has a budget of 3.8 million euro. The aim of the project is to set up a certification process with a standardized quality mark for technical devices for persons with dementia. Products need to complete this standardized certification process, which is universal and applicable. Products are assigned to one of three categories: Enabling / Assistance,- Safety / Security,- Life / Leisure.

To validate products each category uses living labs to test them (four in total). Each living lab works closely with participating people with dementia and their caregivers. The living lab in Krefeld, Germany is based in the Alexian research centre (ARCK). ARCK is part of the non-profit Clinic of Geriatric psychiatry and Psychotherapy, Maria-Hilf-Hospital, Alexian Krefeld GmbH. Participants are recruited through consulting at ARCK, cooperation with general practitioner’s or after stationary stay at the hospital.

The living lab has minimum ten participants per year, who are closely accompanied. Results will be included in trainings and courses. NWE- wide cooperation’s help spreading information. At the moment research is being done on how the products can be tested best and comprehensively (regarding functional and non-functional requirements).

By the end of the project knowledge of technical devices is increased (people with dementia and caregivers know, buy and use assistive products). SME’s are supported.

PO1.2. Apathy and use of Assistive Technology (AT) as predictors of functional performance in Alzheimer’s disease

BREGOLA Allan, TRUCCO Ana Paula, CAMINO Julieta, MIOSHI Eneida
Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, United Kingdom

Background: People with Alzheimer’s disease (PwAD) with marked apathy present with lower functional performance. However, it is not clear whether Assistive Technology (AT) could effectively help improve functional performance. We investigated whether and how apathy and use of AT influence PwAD’s performance, considering level of cognitive deficits.

Methods: Cross-sectional analyses including 99 PwAD. Cognitive deficits (Addenbrooke’s Cognitive Examination-ACE-III; score range 0-100) were defined as Mild-moderate change (MMC:75-100), Moderate-severe change (MSC:39-74) and Severe-very severe change (SVSC:0-38). Disability Assessment for Dementia (DAD) assessed Basic (BADL) and Instrumental (IADL) activities of daily living. Apathy frequency (absent;occasionally/often;frequently/very frequently) was identified through the Neuropsychiatric Inventory (NPI-Q). Information on use of AT included: use of a)Prompts&Reminders; b)Leisure; c)Communication; d)Safety devices. Binary regression models were used to explore the association between apathy (model 1) and use of AT (model 2) on low performance (<80%) of ADLs (BADLs and IADLs). Analysis was repeated for the three groups (cognitive scores).

Results: PwAD mean age was 78.4±6.6 years; 60% were male. Low performance on BADLs was high in all groups; MMC=45.8%, MSC=50% and SVSC=84.2%. Low performance on IADLs was greater: MMC=83.3%, MSC=90.7% and SVSC= 94.7%. In terms of AT, Prompts&Reminder devices were most commonly used (51.1%).

In the MSC, apathy (OR=5.0; 95%CI: 1.1-22.8) and use of Prompts&Reminders (OR=3.2; 95%CI: 1.0-9.9) were associated with low BADL but not with low IADL performance. Nevertheless, when both variables were included in the model, no association between apathy or AT use and BADL performance remained. No significant association was found between apathy or AT use and ADL performance in other groups.

Conclusion: Lower performance in BADLs appears to be associated with apathy and use of AT. However, these effects were seen only when variables were tested independently, suggesting that future research should investigate further the interaction between apathy, AT use and ADL performance.
PO1.3. Does carer management style predict functional performance in medication management in Alzheimer’s disease?

BREGOLA Allan, TRUCCO Ana Paula, CAMINO Julieta, MIOSHI Eneida
Faculty of Medicine and Health Sciences, University of East Anglia, Norwich, United Kingdom

Background: A comprehensive approach comprising good communication, assistive technology (AT) and supportive carer styles seems to benefit functional performance. Less is known about such approach in medication management.

Aim: To explore association of carer management styles with medication management, considering use of AT, number of medications and global cognition.

Methods: Cross-sectional analyses; 99 people with Alzheimer’s disease (PwAD) and family carers. Dementia Management Strategies Scale (DMSS) identified primary carer style: Criticism (CS), Encouragement (ES), Active Management (AMS). Disability Assessment for Dementia (DAD) assessed Initiation and Effective Performance of medication management. Covariates included: use of AT (medication reminders/dispensers), number of medications, global cognition (Addenbrooke’s Cognitive Examination-ACE-III: scores 0-100). Two binary regressions models (Criticism style as reference category) investigated if ES and AMS (independent variables) were associated with dependency in Initiation (dependent variable, model 1) and Effective Performance (dependent variable, model 2) of medication management. Covariates were AT use, number of medications, global cognition.

Results: 32% of carers adopted ES; 25.8% AMS. CS was adopted by most (42.2%). PwAD age was 78±6.6y; 60% male; similar proportions (71%) were dependent in Initiation and Effective Performance of medication management; one quarter (25.3%) used medication reminders/dispensers; average number of medications taken was 4.6±3.3; ACE-III was 55.8±21.2. Carer ES was associated with PwAD’s Initiation of medication management (OR=4.11; 95%CI: 1.31-12.85; p=0.01); no association was found with Effective Performance. ES was marginally associated with Initiation when analysis was controlled by the three covariates (OR=3.45; 95%CI: 0.99-12.05; p=.05). No statistical significance was found between AMS or CS in Initiation or Effective Performance.

Conclusion: Carer Encouragement style seems to support Initiation of medication management to an extent, possibly by overcoming PwAD’s apathy. However, when great number of medications, AT use and severe cognitive deficits are part of the context, carer encouragement alone does not seem to be enough to support functional deficits.

PO1.4. Using Fitbit to record activity levels and sleep quality in people with dementia

GALLAGHER Niamh, DOYLE Priscilla, SMYTH Siobhán, CASEY Dympna
National University of Ireland, Galway, Ireland

This poster outlines the findings on the acceptability and feasibility of using Fitbit to record activity levels and sleep quality in people with dementia, as part of a multi-component psychosocial intervention. Nine community-dwelling people with mild to moderate dementia were asked to wear a Fitbit, day and night, for the duration of an 8-week exercise programme. A key initial finding was that none of the people with dementia owned smartphones. The Fitbits were therefore set up on their primary carers’ phones, with the permission of both parties, and people with dementia were shown how to access their data. People with dementia were asked to charge the Fitbit and sync the device to their carer’s phone weekly. The feasibility and acceptability of wearing the Fitbit was captured via qualitative interviews with people with dementia and their primary carers (n=18). Daily activity and sleep data were extracted to assess wear time and frequency of data synchronisation. The time needed for researchers in relation to initial set-up and follow-up support was also recorded.

Overall, acceptability of wearing the Fitbit among people with dementia was high, and carers were willing to support people with dementia to use it during the study. However, preliminary results indicate adherence to wearing the device over the 8 weeks of the exercise programme was low: wear time was higher for daytime activity tracking than for night-time sleep tracking. Few people with dementia engaged with the Fitbit features, primarily using it to check the time. Carers involvement was essential to facilitate set-up, charging and syncing the device, and technical issues required ongoing support from researchers.

Most people with dementia found the Fitbit acceptable to wear, yet few continuously wore it during the study, suggesting that significant researcher support and carer input would be required to improve adherence in future studies.

PO1.5. Withdrawn

PO1.6. The promise of virtual reality in elderly care: VirtuAAL* project results

GOSPODINOVA Nellie1, MARINESCU Mihaela2, SPIRUI - DAKAS David1, MARZAN Mircea1, BARTOLOME Jose Ignasio3, COLAS Felix4, GAMMELGAARD Mikkel5, VELCIU Magda1, VOICU Andrei1, PAUL Cosmina1, SPIRUI Luiza1

1Ana Aslan International Foundation, Bucharest, Romania, 2Researcher, Bucharest, Romania, 3Ideable Solutions, Biscay, Spain, 4University of DEUSTO, Bilbao, Spain, 5Center for Assisted Living Technology, Health and Care, Aarhus, Denmark
Nowadays, assistive technologies are increasingly used in elderly care. Virtual reality (VR) interventions have already demonstrated their potential for physical and cognitive improvement in people with mild cognitive impairment (MCI) or major neurocognitive disorder. VirtuAAL project aimed to provide innovative solution for combating cognitive impairment using VR technology. It aspired to refine existing immersive serious games and to test the impact of these technologies in older adults who have MCI.

3 VR games on 2 VR systems: HTC Vive and Oculus Go were tested in Romania and Denmark in 2019. Unity was used for the creation of the VR games. In total, 55 older adults in both countries participated in the field trials. End users in Romania were highly educated (superior studies), and had relatively high level of interaction with new technologies and common usage of devices and apps. The games were Kitchen, Forms and Bank. Seniors had to fry eggs, place objects from a table in their corresponding shape, and to withdraw money from an ATM. Field trials tested the usability, accessibility and impact of the VirtuAAL platform.

The results we obtained showed that the 3 games were considered easy and pleasant. Romanian seniors reported that VR interaction was highly immersive, accessible, engaging, and entertaining. Also, usability and timing improved with repeated training on VR. The combination of HTC VIVE glasses and Leap motion was found to be the most successful for the end users and caregivers and it will be the basis of the Kwido VirtuAAL commercial product. VR seems to be a promising field of using ICT in eldercare. Further research would need to focus on studying the impact of VR games on cognitive improvement. New games will be developed with more difficulty levels.

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**PO1.7. The benefit of using indoor technology to decrease the complex effect of elderly social isolation**

VELCUIU Magdalena1, GIANNOGLOU Vasilis2, PAUL Cosmina1, GOSPODINOVA Nele1, POPOIU Oana1, SPIRU-DAKAS David1, MĂRZAN Mircea1, SPIRU Luiza1

1Ana Asian International Foundation, Bucharest, Romania, 2Geoimaging Ltd, Nicosia, Cyprus

There are a number of technological supportive solutions available for dementia and Alzheimer’s disease. The solutions assist diagnosis, care, and aging but there are not many to help prevent the onset of the symptoms of dementia. One out of four people thinks that there is nothing we can do to prevent dementia (World Alzheimer Report, 2019).

This article aims to bridge the gap between elderly people and indoor technologies designed for healthy aging and preventing cognitive decline. Technologies have the potential to cope with loneliness and social isolation factors which beset the risk of developing dementia.

We present the IOANNA integrated solution developed by the “Integration Of All stores Network & Navigation Assistant” project and wisely adapted for elderly needs. It is designed to assist the elderly with their daily activities (street navigation, shopping, chatting, and volunteering), and keep them active, informed, and able to relate to their peer group, carers, and doctors.

A qualitative research method is designed for collecting data using in-depth semi-structured interviews. Twenty elderly, 65 years and over, from Romania and Cyprus, gave us their feedback about the perceived benefits of the prototype. An inductive process was involved to derive the conclusions moving from specific results to broader generalizations and theoretical concepts.

We conclude that the elderly users’ were able to use the technologies to assist them to lead an active, healthy, and interactive life. To increase the technology’s benefits for coping with loneliness and social isolation, the prevention and/or intervention has to be a three-fold approach: a) Customization to adults needs who risk social isolation, b) Integration of a multilayered action by helping in different areas (basic necessities, emergencies, communication, social involvement) and c) Achieving a synergistic effect for preventing the disease before symptoms onset.

**PO1.8. Perceptions of care professionals on e-Health solutions for cognitively impaired community-dwelling older adults and informal caregivers in Flanders and Québec**

DEQUANTER Samantha1, GAGNON Marie-Pierre2, NDIAYE Mame-Awa3, BOUCHER Mylène3, GORUS Ellen4, FOBELETS Maaike1, BUYL Ronald1

1Faculty of Medicine and Pharmacy, Department of Public Health Sciences, Vrije Universiteit Brussel, Brussels, Belgium, 2Research Center on Healthcare and Services in Primary Care of Laval University (CERSSSL-UL), Québec, Canada, Faculty of Nursing sciences, Université Laval, Québec, Canada, 3Research Center on Healthcare and Services in Primary Care of Laval University (CERSSSL-UL), Québec, Canada, 4Faculty of Medicine and Pharmacy, Department of Gerontontology, Vrije Universiteit Brussel, Brussels, Belgium

Purpose: This study aims to understand the perceptions of health care professionals (HCP) on the needs of community-dwelling cognitively impaired older adults and informal caregivers concerning e-Health support in Flanders and Québec. Furthermore, factors related to the use of e-Health solutions in these target groups, as well as to broader implementation in practice are considered.

Methods: Two semi-structured focus groups of HCP were conducted. Altogether, 4 occupational therapists, 2 social workers, 3 nurses, 1 geriatrician, 1 neurologist, 1 general practitioner, 1 manager of a home nursing service, 1 special education technician and 1 physiotherapist participated. Both groups were audio-taped, transcribed verbatim and analysed thematically.
Results: Along with GPS-tracking and personal alarm systems, medication and task management systems are the most observed in practice. These are perceived as beneficial for safety, orientation and functional independence of older adults, and for reassuring informal caregivers and HCP (i.e. therapy compliance). Moreover, they are believed to potentially delay more intensive care (i.e. daycare centre) and lead to more adapted hospital discharges. However, the absence of human aspects in the technology (e.g. in robots) could have adverse effects on well-being. Perceived facilitators for e-Health acceptance were disease awareness, peer support and education, ease of use and customizability, try-out opportunities and longer battery autonomy. Barriers for acceptance were low digital literacy, lack of knowledge on the range of solutions available, high costs, incompatible system language and privacy concerns. All HCP recognized the value of e-Health, however, they lacked reliable information and therefore were highly unsure about recommending them.

Conclusion: Broad support exists for the use of e-Health for community-dwelling cognitively impaired older adults and informal caregivers, however the lack of adequate decision support for HCP interferes with successful implementation in practice. Future research on how to properly educate and support HCP is needed.

PO1.9. RECage project: a prospective cohort study for coping with behavioral and psychological symptoms of dementia

**TSATALI Marianna**1, **POPTSI Eleni**2, **POSSENTI Mario**3, **LAZAROU loulieeta**2, **PARASKEVAIDIS Nikos**4, **FASCENDINI Sara**3, **TSOLAKI Magda**2, **DEFANTI Carlo Alberto**5

1Greek Association of Alzheimer’s Diseases and Related Disorders, Thessaloniki, Greece, 21st Department of Neurology, School of Medicine, Aristotle University of Thessaloniki (AUTH), Makedonia, Hellas, Thessaloniki, Greece, 3Federazione delle Associazioni Alzheimer d’Italia (FAI), Rimini, Italy, 4Greek Association of Alzheimer’s Disease and Related Disorders, Thessaloniki (GAADRD), Makedonia, Hellas, Thessaloniki, Greece, 5Fondazione Europea di Ricerca Biomedica (FERB Onlus), Milano, Italy

Background: Behavioral and Psychological Symptoms of Dementia (BPSD) are some of the most challenging problems arising during the course of dementia, causing severe stress in people with dementia (PwD) and their families. To cope with these symptoms, non-pharmacological treatment is in the first line. Special medical Care Units for people with dementia and BPSD (SCU-B) are residential medical structures, where patients with BPSD are temporarily admitted when their behavioral disturbances are difficult to be managed at home.

Objective: The major objective of RECage project is to assess the SCU-Bs short-term and possibly long-term effectiveness to alleviate BPSD and improve the quality of life of PwD and their caregivers. Methods: The study is a prospective one and 500 persons will be enrolled. 250 patients with dementia, having difficulty-to-control behavioral crises will be recruited by five clinical centers across Europe, and will be admitted to SCU-Bs for a short period of time. The other 250 people will be followed up by six other centers without SCU-Bs via outpatient visits. The study will last for over three years. Statistical analysis will include ANOVA’s and factorial ANOVA for comparison among centers, while a cost-effectiveness analysis will be performed comparing the cohorts. Time to the nursing home placement will be compared between the two cohorts, while analysis regarding the caregiver’s burden in the two will be also applied.

Results: The relative results of the cohort study, will allow adopting a model for each targeted country. Therefore, useful recommendations will be created for the implementation of the intervention in the countries that take part in the study.

Discussion: Based on the RECage project’s expected results, a plan for scaling up the intervention in countries where SCU-B does not exist, such as Greece and Italy will be provided.

PO1.10. Withdrawn

PO1.11. Interactive technologies supporting cognition in people with Dementia – preliminary results!

**GREGERSEN Rikke**1, **SYLVESTERSEN Janna Bohn**2, **HALD Anja**3

1VIA University College, Hinnerup, Denmark, 2VIA University College, Århus N, Denmark, 3Med Tech Innovation Consortium, Århus N, Denmark

Background: Dementia causes cognitive decline in people with dementia (PwD). Cognitive stimulation therapy (CST) is a psychosocial intervention capable of improving cognition in PWD. A Danish version of the certified CST group program has been validated. Now, we are collaborating on Interactive technologies supporting a 12 week’s maintenance program (mCST) to be used in day care facilities. There is high potential with such technology. However, only little efforts have been done so far.

Aim: is to develop a digital prototype of the mCST programme targeted Danish PWD; the product: -1) being user-friendly, intuitive and meaningful; does -2) motivate PWD for programme adherence, -3) promote positive changes in participant’s cognition and quality of life (QOL), and -4) supports CST facilitators.

Methods: The prototype of 24 digitalized mCST sessions will be finished August 2020 and will be tested in a pre-post pilot design at 0, 6 and 12 weeks. Sessions are built in collaboration with technology innovators, PWD, relatives and dementia experts. Ongoing sub parts have been user-tested along the developmental process. The system includes a digital coach assisting participants/staff through sessions. The programme will be facilitated for six outpatients with diagnosed dementia, MMSE 15-25 (2x week in
12 weeks, Aug–Dec 2020). Focus group interviews with participants, relatives and staff at 6 weeks and following programme completion will add data on user satisfaction. Number of completed sessions will be registered and logbooks used. Outcomes on cognition and life quality will be measured by MMSE and QOL at week 0, 6 and 12.

Results: October 2020, we will have preliminary results on programme adherence, user satisfaction with content and technology, and participant’s cognition and QOL results following 6 weeks mCST (first 12 sessions).

Conclusion: The product and preliminary results will be discussed

**PO1.12. Exploring views and needs of (in)formal caregivers towards unobtrusive monitoring in home-based dementia care**

**POREDE Christian, BRAAKMAN-JANSEN Annemarie, VAN GEMERT-PIJNEN Lisette**
Centre for eHealth & Wellbeing Research, University of Twente, Enschede, Netherlands

Background: Extended independent living of people with dementia (PwD) may not only yield immense emotional benefits but also puts more pressure on the (in)formal care network. Novel eHealth-approaches have been developed to delay institutionalization and provide support in home-based dementia care. One innovative approach is unobtrusive in-home monitoring of lifestyle, health and safety using non-wearable sensors (such as Wifi-, radar- or acoustic-based systems) that do not interfere with daily life of PwD. As these technologies develop rapidly it seems essential to keep track of potential users’ needs and attitudes as they too can be expected to change with time. This study therefore aimed to explore the views and needs of informal and formal caregivers of independently living PwD towards unobtrusive in-home monitoring.

Method: We included 35 participants in total. Semi-structured interviews were conducted with informal caregivers of independently living PwD (n=19); focus groups were held with home care professionals (n=16). Both sets of participants were presented with examples of unobtrusive in-home monitoring, followed by questions targeting expected benefits, barriers, needs and privacy concerns. Inductive qualitative content analysis was used to derive themes and categories.

Results: The top 5 desired monitoring targets among both groups included falls, circadian rhythm, nocturnal unrest, eating and personal hygiene. Most dominant benefits included reassurance, better reaction to care needs and the objectivity of monitoring data. Most dominant barriers included attention theft, questionable utility of monitoring in certain cases and the fear of replacing human contact by technology. Privacy concerns appeared to be less of an issue than anticipated. Most participants expressed they would accept a trade-off between privacy vs. the feeling of safety.

Conclusion: The study showed that unobtrusive in-home monitoring brings along new expected benefits and barriers. Potential developers should therefore create tools for helping caregivers and patients in making informed decisions in the future.

**PO1.13. Virtual reality based mindfulness training, sensory activation and assessment for dementia care**

**PALETTA Lucas1, SCHÜSSLER Sandra2, KOBER Silvia Erika3, ZWEYTIK Elke4, STEINER Josef5, ANDREU Jean-Philippe1, FUHRMANN Ferdinand1, GRABHER Andrea5, TABERHOFER Anna2, MAYR Marlene2, STOPPACHER Laura3, LODRON Julia2, PSZEIDA Martin1, DINI Amir1, WOOD Guilherme1, STAUBMANN Wolfgang4, LAMPL Christina6, DRAXLER Theresa5, KÖBL Gertraud4**

1JOANNEUM RESEARCH Forschungsgesellschaft mbH, Graz, Austria, 2Medical University of Graz, Graz, Austria, 3University of Graz, Graz, Austria, 4Sozialverein Deutschlandsberg, Deutschlandsberg, Austria, 5GEFAS Steiermark, Graz, Austria, 6FH JOANNEUM, Graz, Austria

Recent studies underline the importance of cognitive reserve, which is supported by stress reduction, pleasure experience and meditation, for mental health. Mindfulness training is successfully applied to dementia and indicate a lasting positive effect on cognitive reserve, well-being and motivation. The research project OpenSense investigated the potential of VR-based intervention and assessment for dementia care in a proof-of-concept study. The VR-based intervention was developed to foster mindfulness and sensory activation.

VR-based intervention was applied in persons with dementia (PwD) with Alzheimer’s dementia (AD; n=12, age M=85.0 years, MMSE M=21.5) and healthy controls (n=12, age M=75.1 years, MMSE M=30) using 30 minutes of panoramic video-based multi-sensory experiences presenting stimuli that empower relaxation (body-scanning, beach, forest) and activation (bakery, orchestra). EEG-based alpha-band signals (8-12 Hz) associated with relaxation and inhibitory control were recorded before, during and after intervention and eye tracking was applied during intervention.

Pre-post EEG analysis showed significant increases in alpha power and brain connectivity for PwD with AD and controls (post > pre, p<.05). EEG baseline alpha power demonstrated higher values for healthy controls than for PwD (AD). Eye movement analysis demonstrated significant differences between PwD (AD) and controls: eye blink rate AD > controls, p=.004(**); from the observation of a 3 minutes video, and significant correlation (Rho=.607, p=.003(**); 3 minutes video) was achieved between eye movements and the Freiburg Mindfulness Inventory score.
The potential of VR-based intervention based on mindfulness and sensory activation is very promising: the study demonstrated significant increases of EEG alpha power and brain connectivity where PwD usually suffer from decline and gaze data acquired during intervention indicate potential for non-invasive assessment for decision support. OpenSense anticipates numerous opportunities for novel VR-based care services for empowering cognitive reserve, inducing sensory activation, raising awareness and motivation for self-regulation, and as pervasive assessment tool.

**PO1.14. Exploring the impact of a robotic cat for older adults and people with dementia: a scoping review**

**KOH Wei Qi, CASEY Dympna**

National University of Ireland, Galway, Ireland

**Background:** Social robots have been viewed as a type of promising technological interventions to promote the social health of older adults, including people with dementia. Research has shown several benefits of social robots on the psychosocial health of older adults. However, issues such as the high costs can lead to a lack of equal access. The Joy for All robotic cat is designed for older adults, and is substantially more affordable as compared to other pet robots. This scoping review presents synthesized evidence on the use and impact of the Joy for All robotic cat for older adults, including people with dementia.

**Methods:** The Arksey and O'Malley framework was used. Electronic databases and Google Scholar were searched to identify articles. Hand searching and citation searching was also conducted. Intervention studies that used the Joy for All robotic cat, included older adults and were published after 2016 were included.

**Results:** Six papers were included in the final review. Studies were conducted in the United States and the United Kingdom in long term care settings, participants' homes, and an intensive care unit. Most studies were conducted with older adults and people with dementia. Positive impacts from the use of the robotic cat include reduced agitation, improved affect, companionship, and interaction. Staff reported mixed perceptions about the robotic cat. Issues associated with its use include participants' misperception of it as a living animal, users' dislikes, and concerns about infection control.

**Conclusions:** There is a gap in the scientific literature as studies are scarce and existing studies have small sample sizes and lack strong quality. Current findings resonate with the findings from other studies conducted with similar social robots, which facilitated positive psychosocial effects among older people, including people with dementia. However, conclusions are limited. Higher quality studies with larger sample sizes are needed.

**PO1.15. Raising awareness of the use of touchscreen tablets among people with dementia in day care centre**

**MABIRE Jean-Bernard¹, BIZE Klara², COMPERE Florian³, AQUINO Jean-Pierre¹, CHARRAS Kevin¹**

¹Fondation Médéric Alzheimer, Paris, France, ²Université Paris 8 Vincennes Saint-Denis, Saint-Denis, France, ³Université Paris Nanterre, Nanterre, France

**Introduction:** Touchscreens devices are common in our daily environment and are being increasingly used for support and care of people with dementia. The goals of this study were to assess to what extent people with dementia found interest, satisfaction and sense of achievement when using such devices, and if individual or group sessions were more suitable for learning how to use them.

**Methods:** The study involved 27 people with dementia attending two different day care centers in Paris suburbs. They were divided into five groups: three individual learning sessions (one tablet for each participant) and two group learning sessions (one tablet for two participants). The intervention consisted of eight 30-minute sessions with three facilitators. Each session consisted in learning basic functions, discovering specific features and enabling leisure time or free exploration. Interest in the use of tablets was assessed through direct observation and a pre-post intervention questionnaires. Satisfaction was assessed after each session with a questionnaire. Usage was evaluated in terms of amount of help needed, steps required and achievement score.

**Results:** At first sight, participants showed moderate interest for tablets. However, satisfaction of use during sessions was high. Average scores of achievement and for carrying out basic actions increased during the first sessions and then reached. Difficulties encountered by participants included tactile sensitivity, forgetting steps to be carried out from one session to the next, and distractions caused by unintended notifications.

**Conclusion:** People enjoyed learning sessions but did not express a significant amount of interest in the use of touchscreen devices in daily life. Offering more frequent sessions and a relay at home could promote empowerment of people with dementia when using touchscreen tablets. We need more studies to investigate personal interests of people with dementia for touchscreen tablets, and how to adapt learning and daily use.
PO1.16. Smart big data platform to offer evidence-based personalized support for healthy and independent living at home

POPOIU Oana, SPIRU Luiza, MARZAN Mircea
Ana Aslan International Foundation, Bucharest, Romania

SMART BEAR is a multi-centric observational research study (5 large-scale pilots, spanning 6 different countries – Greece, Italy, Portugal, France, Spain, Romania), aiming to implement state-of-the-art technology in the everyday life of elderly citizens with specific health challenges (including cognitive deficits, anxiety, depression and frailty) by integrating off-the-shelf friendly to use devices into an innovative platform – SMART BEAR platform.

The SMART BEAR platform will act as an assisting and personalized tool for daily routine, integrating data collected through sensors, assistive smart medical devices and end-user input via structured questionnaires and interaction.

The Romanian pilot is conducted by ANA ASLAN International Foundation, an European Excellence Center for Neurocognitive Diseases (info.eadc) and a Geriatric/Gerontology and Old Age Psychiatry Excellence Center for Romania.

Digital technologies as in SMART BEAR could contribute by cognitive stimulating serious games, lifestyle coaching for healthy dietary habits, physical and social activities, measuring performed activities, monitoring subsequent pathologies and therapy adherence, supporting better indoor orientation (intelligent lightings and sensors) and safer outdoors travelling (GPS location trackers).

Primary objective: the correlations between the compliance with the recommended interventions and the individual evolution on the cognitive status. The hypothesis is that participants with increased adherence to the recommended interventions (serious games-3 sessions/week, physical activities - minimum 150 min/week) and social interaction, will have better outcomes compared to those with lower adherence.

Secondary objective: the correlations between continuously monitored lifestyle parameters, (e.g. sleep quality) and individual cognitive & functional outcomes. The hypothesis is that better sleep quality will be correlate with better cognitive outcomes.

Novel technologies such as those to be employed in the SMART BEAR project have indeed the potential to benefit, assess, monitor and support older people to live independently and improve their quality of life.

This project has received funding from EU’s Horizon2020 R&D programme under GA No.857172

PO1.17. Collaborative partnership among families with dementia and professionals on development of tools to enable personalized communication about everyday technology

PEOPLES Hanne1, KOLDBY Kim2, HANSEN Mette Hartvig2, BOJEN Lars2, NIELSEN Lasse Overballe3
1Faculty of Health Sciences Health Sciences Research Centre, UCL Department of Rehabilitation, SDU, Odense, Denmark, 2UCL University College, Odense, Denmark, 3Linne University, Växjö, Sweden

Background: It is known that technology has the potential to support and facilitate everyday living for families with dementia, e.g. by enabling people to continue meaningful activities and to stay connected with family and friends. However, little is known about ways to facilitate collaboration and involvement among families with dementia and health professionals in regards to this area. Accordingly, the purpose was to investigate ways to personalize communication and shared-decision making on the use of everyday technology to improve the overall quality of municipality service in this area.

Methods: This project was based on ideas of design thinking and theory of change. The data comprised semi-structured interviews, focus groups and participant observation. The project involved three stages of exploration and tool development, followed by a six months pilot test. The sample consisted of 83 participants: 47 health professionals, 33 people with dementia and 3 relatives. A thematic analysis let to the findings.

Results: This project was initiated and funded by ‘The Development Center for Dementia’, which consists of eight Danish municipalities and two health educations. The study resulted in three interrelated tools: 1) a set of dialogue cards to promote person-centered communication and shared-decision making about technology to support everyday living, 2) A concept for developing health professionals’ technology skills, and 3) A technology catalog that can be used across municipalities.

Conclusion: This project resulted in three tools, which combined contribute to a more personalized and user-friendly approach to communication and dissemination about everyday technology, that may inspire quality development. Using these tools, families with dementia are invited to participate in a dialogue about technology in relation to their everyday lives, as opposed to a more traditional screening of needs.

PO1.18. Development of a digital resilience monitor for informal caregivers of persons with dementia to prevent crises

OOSTRA Dorien, NIEUWBOER Minke, OLDE RIKKERT Marcel, PERRY Marieke
Radboudumc Alzheimer center, Nijmegen, Netherlands

Background: The number of people with dementia living at home increases, resulting in a growing societal dependency on informal care. Informal caregiving causes a considerable physical and mental burden on
caregivers’ wellbeing, which is often a direct reason for crisis admission of the person with dementia. Monitoring caregiver’s wellbeing and resilience followed by early intervening by case managers may prevent crisis. Our aim is to develop and test a user-friendly digital monitor to assess wellbeing and resilience of caregivers and enable case managers to provide timely support.

Methods: A human centered design method was used to identify wishes and needs, develop ideas and test visual prototypes of the monitor. Focus groups with end users and experts in the field of primary dementia care took place. End users were caregivers and professionals from different disciplines. Experts were researchers, clinicians, innovation experts and application designers.

The 3-month pilot study includes caregivers and case managers and consists of monitoring wellbeing and resilience weekly by a set of questions. Intervention delivery and acceptability will be assessed via a questionnaire and interview.

Results: Wishes, needs and functionalities were identified during two focus group meetings. To detect deterioration of caregivers’ wellbeing earlier, a digital tool connected to a dashboard for case managers is desired. To assess wellbeing, questions were reviewed during a third meeting covering the topics: social support, reciprocity, burden, mood, own activities, small crises, person with dementia. Caregivers want to fill in approximately seven questions per week.

Preliminary results of the pilot study will include adherence, user satisfaction and usability.

Conclusion: This methodological approach will result in a product that best meets the needs and wishes of caregivers and case managers in order to prevent crises. The pilot study will provide insight into the possible effectiveness and usefulness of this product in practice.

PO1.19. A companion robot pet; the experiences of residents living with dementia in long-term care

CARRAGHER Lucia¹, MARRON Ann²
¹NetwellCasala, Dundalk Institute of Technology, Dundalk, Ireland, ²Health Service Executive (HSE), Dundalk, Ireland

Two-thirds of nursing home residents have dementia and up to 90% have behavioural and psychological symptoms of dementia that may be related to unmet need. With the incidence of dementia rising sharply at ages greater than 75, the demographic trend towards an increasingly older population is expected to result in a tripling of dementia cases by 2050. To maintain high quality care, and contain costs, innovative solutions are urgently needed.

Artificial intelligence robots offer new possibilities for psychosocial interventions, but uptake remains low. This study explores the impact of a companion robot pet on residents’ stress, mood, social engagement with other residents and staff and quality of life in general. We recruited 12 residents from a nursing home in Ireland and allocated 6 to the intervention group and 6 to the control group. Residents in the intervention group, received three facilitated 15 minutes sessions each week between 1-5pm. Residents in the control group received usual care. We carried out video observations using small action cameras, before, during and after each intervention.

The primary outcomes of interest include:

Agitation—measured by Cohen-Mansfield Agitation Inventory-Short Form (CMAI-SF; 14 short-item).

Mood and engagement—measured from video observations.

Facial emotional responses—measured using ‘Observed Emotion Rating Scale’ (pleasure, anger, anxiety or fear, sadness), and coded by frequency.

Engagement—measured by duration, visual and verbal alertness e.g. interest in robot, watching and interacting with it, maintaining eye contact, talking to it.

Non-engagement (not watching robot, avoiding eye contact).

Verbally engaged/not (e.g. participating in conversation, initiating statements/not).

Social interaction—each instance where a participant uses the robot to interact with others is coded.

Secondary outcome measures include staff and family perceptions.

Full results available in June 2020.

Ethical approval for this study was granted by the Ethics Committee, School of Health and Science, DkIT.

PO1.20. Understanding the barriers and facilitators affecting the implementation of social robots for older adults including people with dementia: a scoping review

KOH Wei Qi¹, FELDING Simone Anna², CASEY Dympna¹
¹National University of Ireland Galway, Galway, Ireland, ²DZNE German Center for Neurodegenerative Diseases, Dortmund, Germany

Introduction: Psychosocial health issues among older adults, such as depression and social isolation are an important cause of morbidity and premature mortality for older adults. People with dementia are particularly at risk. With a rapidly aging population, these issues are expected to be amplified. Studies have reported positive findings regarding the effects of social robots on the psychosocial health of older adults, including people with dementia. Nevertheless, little is known about factors affecting their implementation in real-world practice.
Objectives: The objectives of this review are to synthesize variants in terminologies that are used to describe the implementation of social robots in the current literature base, and to identify barriers and facilitators affecting their implementation in practice.

Methods and analysis: This study follows Arksey and O'Malley's approach with methodological enhancement by Levac at al. The taxonomy of implementation outcomes is used to guide the systematic search in electronic databases. Reference searching and hand searching will also be conducted. A two-phased article screening and selection process is undertaken by two independent reviewers. Findings will be collated and reported thematically based on domains in the Consolidated Framework of Implementation Research (CFIR). The Preferred Reporting Items for Systematic Reviews and Meta-Analysis extension for scoping reviews (PRISMA-SCr) will be used to report findings.

Results and Findings: We are currently at the phase of searching, screening, and selecting articles to be included. The outcomes of this scoping review include synthesized literature regarding barriers and facilitators affecting the implementation of social robots, and variants in terminologies used to describe “implementation”. Research gaps will be identified to guide further empirical research in this field. This evidence synthesis constitutes part of a bigger project aimed to develop implementation guidelines for social robotics for people with dementia.

PO1.21. Promoting the adoption of wearable GPS technologies in dementia care: key lessons from focus group interviews with business, research and healthcare professionals

FREIESLEBEN Silka Dawn, ROESCH Christina, MEGGES Herlind, PETERS Oliver

Charité – Universitätsmedizin Berlin, Memory Clinic and Dementia Prevention Center, Berlin, Germany

Objective: Wearable global positioning system (GPS) technologies can aid persons with dementia (PwDs) to remain independent longer by helping manage orientation impairments. However, they are underused in dementia care. Information on barriers to adoption, product-service requirements and marketing strategies from a broad multi-actor perspective is limited, particularly from business professionals.

Methods: We conducted a mixed-methods, focus group interview study with 22 professionals from business, healthcare and research fields. Topics ranged from examining in-depth thoughts on product requirements (design and functions), barriers to adoption, product-service requirements and marketing strategies. Also, product testing was performed to simulate real-life user experience and to supplement discussion insights. Thematic analysis was performed. Quantitative data included demographics, experience with dementia and assistive technologies (years), pay willingness for a GPS watch (once/per month), the technological affinity scale for electronic products (TA-EG; range 19-95), and the ISONORM 9241/10 scale (range 0-210).

Results: Professionals’ mean age was 42 years (SD=11.5), almost half were male (45.5%), and approximately half had five or more years experience with dementia (54.5%) and assistive technologies (45.5%). Analysis of quantitative data revealed no significant group differences. Five main themes on barriers to adoption emerged: (1) awareness and experience, (2) technical limitations, (3) unclear benefits, (4) data security and (5) product pricing. Business professionals also reported on legal aspects, capital investment limitations, and the mismatch between end-user needs and available products. Business and healthcare professionals further reported on unsatisfactory aesthetics. Several product-service requirements (e.g., technical assistance and innovative charging options) and marketing strategies (e.g., trial phase testing and involvement of respected institutions) were discussed.

Conclusion: Our results provide a multi-actor, qualitatively rich picture on the barriers to adoption of wearable GPS technologies in dementia care and present possible product-service and marketing solutions to address these limitations. Business professionals provided insights largely overlooked in the existing literature.

PO1.22. Impact of assistive technologies on cognitive decline among senior mild cognitive impairment patients

VOICU Andrei¹, SPIRU Luiza¹, PATERNO Fabio², MANCA Mario², BANAJ Nerisa³, DICK Maximiliand

¹Ana ASLAN International Foundation, Bucharest, Romania, ²Consiglio Nazionale delle Ricerche, Pisa, Italy, ³RCCS Santa Lucia Foundation, Rome, Italy, ⁴Bartenbach GmbH, Aldrans, Austria

Introduction: Mild Cognitive Impairment (MCI) describes an intermediate stage between physiological aging processes and dementia, often a transitional state, but not always - the 32% rate of progression to dementia was the aspect research has focussed more on. The Personalizable assisTive Ambient monitoring and Lighting (PETAL) Project represents a unique and innovative solution that aims to reduce the cognitive decline among MCI patients through an assisted ambient environment and use of neurocognitive stimulation applications.

Materials and Methods: PETAL involves an ongoing prospective observational study based on 2 field trials, the 2nd currently being in progress. In the first one, 6 patients from 2 countries (Romania and Italy) were enrolled. Patients underwent a cognitive and functional assessment before and after the trials – MMSE Test, Verbal Fluency, Rey’s Figure and Auditory Verbal Test. Quality of life was assessed through QoL-AD, ADL and iADL scales while psychiatric manifestations through Neuropsychiatric Inventory (NPI).
Results: Patients were 2 males and 4 females, age between 76 and 83 with a median of 80.5 years. Cognitive evaluation showed 1.375 points (25.6%) increase in MMSE Test, 2 points (15.38%) increase in Verbal Fluence and 1.75 (13.33%) increase in Semantic Fluence. Quality of life recorded 0.25 points (4.35%) increase on ADL and 0.625 points (9.72%) on IADL. NPI results revealed: depression – 0.6 points (35.71%) drop in frequency and 0.125 points (16.67%) in severity; sleep - 0.625 points (33.33%) drop in frequency and 0.25 points (22.22%) in severity.

Discussions and Conclusions: Patients showed a slight increase in neurocognitive functions, quality of life as well as neuropsychiatric symptoms. Increase in verbal fluence test score is perhaps one of the most promising results. This system also helped in consolidating patient independence by increasing quality of life. However, further and larger studies should be conducted.

POI1.23. The potential of augmented reality services for assisting activities of daily living in dementia care

PALETTA Lucas1, TATZER Verena C.2, SCHÜSSLER Sandra3, GLEIXNER Günther4, GÄRNER Dominik5, STEINER Josef6, GINDL Sophie5, VOITHOFER Claudia3, LIN Simon6, ANDREU Jean-Philippe1

1JOANNEUM RESEARCH Forschungsgesellschaft mbH, Graz, Austria, 2Fachhochschule Wiener Neustadt, Wiener Neustadt, Austria, 3Medical University of Graz, Graz, Austria, 4ar:met GmbH, Graz, Austria, 5Sozialverein Deutschlandsberg, Deutschlandsberg, Austria, 6Symptoma GmbH, Salzburg, Austria

The increased demand for health services in dementia means a gap in the provision of care by nursing and health professionals. People in the early stages of dementia live mainly at home. One of the most important tasks is to promote the independence and intrinsic capacity of people with dementia to live as long as possible at home, taking into account the stage of dementia and individual abilities.

The AR-Demenz research project investigates Augmented Reality (AR) assistance technologies with the intention of supporting goal-oriented self-efficacy and thus an autonomous, as independent as possible life for people with dementia living at home. The focus is on assessing the application potential of AR-supported platforms (smartphones, tablet PCs, increasingly miniaturized data glasses) which open up new interaction potentials and are outstandingly suited for intuitive operation and assistive functions.

We present first results from our research about the dimensions of necessary requirements involving different groups of actors, such as, people with dementia, relatives, nursing staff, occupational therapists, experts from information technology, geriatrics and psychology, dementia-friendly communities. We outline relevant application scenarios in AR-supported accompaniment in activities of daily living, such as using remote assistance technology by people with dementia, there relatives and health care staff for dressing, cooking and communication. Furthermore, we evaluate AR-based motivational activation including assessment of executive functions by means of 3D-interaction games that are inspired by ‘Tower-of-London’ and ‘Kitchen Task Assessment’. Finally, we present results from the first field study about the usability of these innovative components.

The key outcome of AR-Dementia is the evaluation of the potential of AR-assisted assistance to foster self-care, self-regulation, and activation for interventions. The definition of necessary framework conditions for technology, usability and resources is a fundamental basis for new assistance solutions with a large projection for future strategies in dementia care.

POI1.24. Palliative Care in Dementia: Recognising Signs and Symptoms of End Stage Dementia

HENRY Gayle
Dementia Service Development Centre, Stirling, United Kingdom

Appropriate management of advanced dementia requires understanding that it is a life limiting condition without curative treatment, interventions should be chosen carefully ensuring improvement or maintaining quality of life without burdensome interventions (Kumar & Kuriakose, 2013). Evidence indicates palliation is not undertaken due to lack of recognition the person with dementia’s condition is deteriorating, lack of staff confidence and systemic barriers. The clinical features of end stage dementia are not always recognised by clinicians leading to sub-optimal end of life care (Potter, Fernando & Humphel, 2013).

Dementia begins by affecting the brain often progressing to affect the whole body, changing focus from active medical treatment to palliative care although literature recognises it is difficult to provide accurate estimation of life expectancy. Dementia may have a prolonged decline with severe disability (Van der Steel, 2014), dementia specific palliative care strategies require consideration of co-morbidities and managing behavioural problems possibly manifesting due to unmet physical needs (James & Jackman, 2017).

Clinicians require abilities to anticipate, assess and manage physical and cognitive problems, facilitate communication with the person with dementia also families and/or carers allowing opportunity for support and preparation. Knowledge of the clinical signs and symptoms of deterioration can assist in addressing end of life issues effectively although Palliative and End of Life care for individuals with dementia is often longer than with other chronic conditions a tool to guide staff may be of benefit.
As part of a research project undertaken in Australia in 2013 to identify signs and symptoms of end stage dementia a care plan was devised to assist carers in recognising deterioration and respond effectively. This care plan was trialled in the intervention cohort and utilised by an aged care organisation.

**PO1.25. Feasibility and usability of smart-phone based experience sampling in people with MCI**

BARTELS Sara Laureen¹, VAN KNIPPENBERG Rosalie², MALINOWSKY Camilla³, VERHEY Frans², DE VUGT Marjolein²

¹Maastricht University, Stockholm, Sweden, ²Maastricht University, Maastricht, Netherlands, ³Karolinska Institutet, Stockholm, Sweden

**Background:** Daily functioning of people with cognitive disorders such as mild cognitive impairment (MCI) is usually depicted by retrospective questionnaires, which can be memory-biased and neglect fluctuations over time. This study examines the feasibility and usability of applying the experience sampling method (ESM) in people with MCI to provide a detailed and dynamic picture on behavioural, emotional, and cognitive patterns in everyday life.

**Methods:** Twenty-one people with MCI used an ESM app on their smartphones for 6 consecutive days. At 8 semi-random timepoints per day, participants filled in momentary questionnaires on mood, activities, social context, and subjective cognitive complaints. Feasibility was determined through self-reports and observable human-technology interactions. Usability was demonstrated on an individual and group level.

**Results:** Three participants dropped out as they forgot the study instructions or to carry their smartphones. In the remaining 18 individuals, compliance rate was high with 78.7%. Participants reported that momentary questions reflected their daily experiences well. 71% of the participants experienced the increased awareness of own memory functions as pleasant or neutral. Subjective cognitive functioning showed great between- and within-participant variability.

**Conclusion:** This study found evidence for the general feasibility of smartphone-based experience sampling in people with MCI. Momentary data can increase the insights into daily pattern and may guide the development of self-management strategies in clinical settings. However, many older adults with MCI are currently not in possession of smartphones and study adherence seems challenging for a minority of individuals.

**PO1.26. Withdrawn**

**PO1.27. Withdrawn**

**PO1.28. DS-AGEING - cognitive training programme for healthy and well-ageing of people with Down Syndrome**

L. ZLOBEC Štefanija, KRIVEC David, BASTARDA Maša, KEČKEŠ Polona

Spominčica - Alzheimer Slovenia, Ljubljana, Slovenia

DS-AGEING project (Erasmus+ KA2), aiming at improving well-ageing of persons with Down Syndrome with special regard on cognitive training, facing transition events, autonomy at ADL activities and social inclusion. Persons with Down Syndrome are more prone to premature ageing and cognitive decline soon after they turn 30 years old, so the likelihood ratio for them to develop young onset dementia, is quite high. In order to postpone first signs of dementia, they should be actively involved in cognitive simulative activities and actions.

Through the course of the project, consortium of 5 European countries (Spain, Romania, Greece, Portugal and Slovenia) enhanced and promoted competences (knowledge, skills, attitude) how to keep quality of life of PDS on one hand and cognitive resilience on the other hand. Project partners have developed educative training materials with templates for experiential activities, organized into 6 to 8 sessions per dimension. Each session consists of face-to-face session or practical/e-training activity with combination of exercises and tasks from real-life situations that will contribute to better daily functioning. To properly meet the needs of PDS, contents and structure of training materials were designed within co-creation sessions in collaboration with end-users and professionals.

Moreover consortium launched e-platform with useful references and resources on why issues with Down syndrome and mild cognitive impairment/dementia ought to be tackled together and not separately. E-platform is accessible at the following link: https://www.dsageing.eu/. As a project partner Spominčica-Alzheimer Slovenia brought a special attention how dementia affect cognitive process and what we should take into account when developing training materials for persons with cognitive decline. DS-AGEING project, that started in 2018 and ended in September 2020, offers an innovative training package for PDS and their caregivers or guardians, who complain about lack of productive educative materials for cognitive training of PDS who are over 30.

**PO1.29. Interaction style and assistance given by carers of people with dementia during the performance of daily tasks. A novel observation scale**

CAMINO Julieta¹, BACKHOUSE Tamara², KISHITA Naoko², MIOSHI Eneida³

¹University of East Anglia, Norwich, United Kingdom, ²Dr, Norwich, United Kingdom, ³Prof, Norwich, United Kingdom
Background: As people with dementia (PwD) progressively decline when performing daily tasks, family carers become the main providers of support. At times, carers provide more support than required, which could lead to PwD faster decline and carer exhaustion. Measuring reliably the assistance and interaction style used could lead to tailored interventions that promote function while reducing carer’s time providing assistance.

Objective: to develop an observational scale to measure interaction style and assistance given by carers during tasks.

Methods: fifteen PwD (Alzheimer’s disease) with family carers were video-recorded during the performance of a task - preparing a fruit salad- with carer support. To develop the scale, two researchers observed two video-recordings independently, made detailed notes of types of interaction and assistance present. These notes formed the basis of the tool (first iteration). The researchers then independently scored the same interactions and two new videos with the prototype tool. The tool was refined (second iteration) and used to score 13 new videos. These observed interactions were transcribed and 96 quotes were re-scored and cross-checked between the two researchers.

Results: A novel 21-item scale gathers information about interaction style and assistance given by the carer during task performance. Items on the scale comprise two main categories: communication-related-interactions and assistance-given-related-interactions. The scale also allows the observer to obtain information about the level of assistance requested by the PwD and the amount of supervision given by the carer while the task is completed.

Discussion: Using a novel observation scale to measure interaction style and assistance given by carers when PwD completing tasks can help to understand the support needed by the PwD and how much assistance a carer provides during tasks. Future interventions could target carers’ skills on how best to support PwD during task performance.

PO1.30. The added value of art for caregivers and artists and people with dementia living in nursing homes

BOERSMA Petra1, BOUMAN Margreet2, KERKVLIET Tanja2, VAN DER PLOEG Tjeerd3, GOBBENS Robbert4

1Inholland University of Applied Sciences, Amsterdam, Netherlands, 2Art in Education and Society, Scholen in de kunst [arts education centre], Amersfoort, Netherlands, 3Faculty Engineering, Design and Computer Science, Inholland University of Applied Sciences, Alkmaar, Netherlands.

Art plays an important role in the promotion of health and well-being for older people. Therefore, Schools of Art in Amersfoort, the Netherlands, has developed five art-based day-activities for older people with dementia and psychiatric diseases living in a long-term care-facility; (a) music and movement, (b) visual arts, (c) dance, (d) time slips and (e) theatre based on fantasy stories. The art-activities are developed and executed by artists and caregivers together. Two of the five art-activities are included in the present study, (a) music and movement and (b) visual arts. The aim of this study is to give insight into how art-activities influence the mood and quality of life of residents with dementia, and how the artists and caregivers collaborated in offering the cultural interventions.

An uncontrolled pre- and post-test study was conducted using a mixed-method design. FACE (Whaley & Wong, 1987) was used to examine to what extent participating in the art-activity influences the mood of the residents. In addition, qualitative data were collected by means of group-discussions with artists and caregivers and one informal caregiver.

Sixteen residents participated in the study. Results showed that participating in an art-activity positively influences the mood of people with dementia (p=0.048 for music and movement; p=0.023 for visual arts). The qualitative data revealed that joining an art-activity provides a positive affect, increases social relationships and improves the self-esteem of the residents. The collaboration between artists and caregivers stimulates creativity, they learned from each other’s expertise and together, they created beauty and evoked emotions.

This study demonstrated that arts has a positive influence on the well-being of older people with dementia; in addition, interprofessional collaboration had an added value for both, the artists and the caregivers.

PO1.31. Experiences of people with dementia and carers participating in a complex psychosocial intervention (CREST)

O’SULLIVAN Grace, CASEY Dymphna, SMYTH Siobhán, GALLAGHER Niamh, DOYLE Priscilla

National University of Ireland, Galway, Galway, Ireland

A dementia diagnosis can prevent people from participating in society, leading to a further decline in cognitive, social and physical health. However, it may be possible for people with dementia to continue to live meaningful lives and continue to participate actively in society if a supportive psychosocial environment exists. A pilot study was conducted to determine the feasibility and acceptability of a multifaceted complex resilience-building psychosocial intervention for people with dementia and their carers living in the community. Outcomes assessed the feasibility and acceptability of all study processes and this paper will report specifically on the intervention content and delivery.
Preliminary results indicate that participants (people with dementia and carers) enjoyed the content of the CREST intervention, that the delivery method and timing worked well and overall found the programme beneficial. Carers reported that the educational programme provided them with valuable information which was accessible and easy to understand. However, the group activities and learning from each other was identified as crucial to their enjoyment and learning. People with dementia enjoyed the Cognitive Stimulation Therapy (CST) and exercise components, some reporting that the CST enhanced their concentration and that exercising with an exercise partner was more sociable and enjoyable.

Evidence from participants indicates that the manualised intervention content and delivery methods of CREST were feasible and acceptable to carers and people with dementia in the community.

**PO1.32. Exploring the feasibility of a complex psychosocial intervention (CREST) for people with dementia and carers**

DOYLE Priscilla, GALLAGHER Niamh, SMYTH Siobhán, CASEY Dympna

National University of Ireland, Galway, Galway, Ireland

Pilot studies are essential in assessing the acceptability and feasibility of interventions and study protocols in order to avoid the cost of failed trials. Ten people with dementia and their primary caregivers living in the community were recruited and received the complex psychosocial CREST intervention. This paper reports on the recruitment strategies and the feasibility and acceptability of the secondary outcome measurement tools (completed pre- and post-intervention). Recruiting participants was difficult, with local community organisations/groups proving a more successful strategy than using GP practices. Researcher time required for recruitment and data collection were recorded, alongside participant barriers for non-participation. The time required for recruitment was targeted at five months, however this had to be extended to eight months. The participant information leaflet and consent form were reported to be informative and easy to understand, thereby assisting recruitment. In particular, value was placed on face-to-face meetings with researchers, accessibility to the research team, and reminder letters and follow up phone-calls.

The secondary outcome tools included; Quality of Life-Alzheimer’s Disease, Mini Mental State Examination, Geriatric Depression Scale, Stigma Impact Scale, Positive Psychology Outcome Measure and the EQ-5D-5L. Caregivers completed; Zarit Carer Burden Interview, Short Sense of Competency Scale, Dementia Knowledge-20, Resource Utilization in Dementia and the Adult Carer Quality of Life. People with dementia preferred the tools to be administered while carers preferred to self-complete. Most carers and people with dementia rated the tools as easy to complete and on average completed them within the recommended time, with exception of the Stigma Impact Scale, which some people with dementia found challenging.

This feasibility data will help to optimise recruitment to a future RCT trial and confirms the acceptability of the secondary outcome measures.

**PO1.33. Seen as a person: digital art promoting social interaction between dementia residents, families and carers**

TAN Josephine Rose¹, BOERSMA Petra², AEGERTER Laurence³, ETTEMA Teake¹, STEK Max⁴, GOBBENS Robert², DRÖES Rose-Marie¹

¹Amsterdam UMC, location VUmc, Department of Psychiatry, Amsterdam, Netherlands, ²University of Applied Sciences, Inholland, Amsterdam, Netherlands, ³Visual Artist, Amsterdam, Netherlands, ⁴Regional Mental Health Organisation GGZ in‘t Veld, Department of Old Age Psychiatry, Amsterdam, Netherlands

Viewing of artistic photos have been found to enhance the engagement of persons with dementia in meaningful interactions, thus improving their social health and quality of life. Still, there is a lack of such psychosocial interventions for people with more advanced dementia in nursing homes. In a recent small-scale pilot study, we (Theismeijer et al., 2018) explored the effects of a person-centred, photo-activity using different kinds of artistic photos on people with moderate to severe dementia in nursing homes. The experimental group was shown person-oriented photos (related to their personal interests, inventoried via informal caregivers) while the control group was shown non-person-oriented photos. Although no statistical significant differences in degree of social interaction and mood were found, calculation of effect sizes showed that person-oriented photos seemed to have a more positive impact on these outcomes (moderate to large effect sizes). It is possible that no significant differences were found due to the study’s small sample size.

The current study builds upon Theismeijer et al.’s (2018) findings. It aims to develop a digital version of the photo-activity intervention, to investigate its impact on social interaction, mood and quality of life of people with advanced dementia in nursing homes, and to investigate the intervention’s impact on person-centred attitude and sense of competence in (in)formal caregivers. The intervention’s feasibility and effectiveness will be investigated through a randomised controlled trial involving 150 nursing home residents with dementia and their (in)formal carers, with three measurements (before/after 3-months intervention, and follow-up). A process analysis will determine the facilitators and barriers to the intervention’s implementation. It is expected that the residents will feel acknowledged as a unique person with their own experiences, while their caregivers will develop a more person-centred attitude.

This study is funded by the EU and will be conducted within H2020-MSCA-ITN-2019 (DISTINCT: 813196)
PO1.34. Building a realist programme theory for a novel multi-sensory intervention

D’ANDREA Federica1, TISCHLER Victoria2, DENING Tom3

1University of West London, London, United Kingdom, 2School of Nursing, Midwifery and Healthcare, University of West London, Brentford, United Kingdom, 3Division of Psychiatry & Applied Psychology, School of Medicine, University of Nottingham, Nottingham, United Kingdom

Multi-sensory intervention is a sensory stimulate approach that has received great interest within the field of dementia treatment, particularly for the management of responsive behaviours. The encouraging results on handling objects activities and the unique relationship between olfaction, memory, and emotion, prompts the interest to develop a multi-sensory intervention (MSI), using olfactory, tactile, and visual stimulation for people with dementia living in care homes.

The Medical Research Council guidelines for the development and evaluation of complex intervention recognises the need to optimise complex interventions by building underlying intervention theory and mechanisms prior to full trial. This knowledge produces critical information to increase the likelihood of successful intervention delivery and implementation. The current study describes a phased approach to data collection and analysis used to define and refine the components and intended mechanisms of action of MSI; specifically understanding in what ways MSI works, how optimum outcomes are achieved, and how contexts influence the outcomes.

A mixed-method, multi-stakeholder study was designed within a realist evaluation conceptual framework. This included the development of an initial programme theory by scopig the literature and qualitative data gathered from interviews with academic experts and healthcare professionals. A realist synthesis of the literature and a modified Delphi panel approach with a healthcare professional, informal caregivers, and academic experts will be used to refine and test the programme theory.

The presented study supports the development of a theory-driven novel intervention for people with dementia and offers an important contribution to the growing literature on methods to improve intervention design and reduce implementation failure.

PO1.35. Withdrawn

PO1.36. The social impact of participating in football for people living with dementia

MACRAE Rhoda

University of the West of Scotland, Hamilton, United Kingdom

Inclusive and modified sport promotes opportunities for participation often for older people or people with disabilities, physical and or mental health issues. Walking sports, a form of modified sport, often with a focus on people over 50 years, are designed to support people to engage in physical and social activity. We will present the findings of a qualitative study that explored how walking football sessions were designed and delivered for people living with dementia. The study illuminates the social impact of participation and demonstrates the ways people living with dementia can have agency and strong embodied identities. We also propose best practice recommendations for those organising the increasing number of modified sports activities being offered for older people living with dementia.

PO1.37. Physical and mental wellbeing during the Covid-19 crisis

BURGUI Diana

Dementia Services Information & Development Centre, Dublin, Ireland

The Covid-19 pandemic has brought much hardship and suffering to our communities. People with dementia and their caregivers and families have been particularly badly affected, whether they are residing in nursing homes or in their own homes. For those living at home the results of a recent survey highlighted that loneliness, boredom and anxiety are particularly prevalent and that there was an increased need for alternative supports for people with dementia, carers and families. (Covid-19: Impact & Need for People with Dementia and Family Carers, Alzheimer Society of Ireland report, 2020)

In response to the COVID-19 crisis, the Dementia Services Information and Development Centre (DSiDC), working collaboratively with the Health Service Executive and the Alzheimer Society of Ireland, developed a collection of online information resources. These information leaflets are divided into sections that address the medical, practical and emotional aspects of living with Covid-19 and dementia.

They are designed to respond to to the needs of people with dementia, carers and families and cover the themes of gardening, exercise, music, the arts and museums, lifestyle, reminiscence, video calling and cocooning. They provide practical advice and links to verified resources to help people keep physically and mentally active during the Covid-19 crisis and to minimise or prevent emergent non-cognitive symptoms of dementia (NCSD). The leaflets have been well received and have been widely shared in social media networks and publicised by other institutions worldwide.

The leaflets are based on research evidence from a 2019 DSiDC guidance document commissioned by the Irish National Dementia Office (NDO). The guidance, aimed at healthcare professionals, focused on the effectiveness of non-pharmacological interventions for people who were experiencing NCSD. This document was designed to accompany new national clinical guidelines for physicians on the appropriate prescribing of psychotropic medication for non-cognitive symptoms in people with dementia (DoH, 2019).
Covid-19 pandemic officially broke out in Italy on February 21st, figures up to May 10th indicate 218,000 infected and 30,395 deceased. Mean age of deceased persons was 80 yrs, women representing 39,1%. Median age of those who died was 20 yrs higher than infected survivors. Elderly and fragile people being the most vulnerable, Meeting Centers, Alzheimer Cafés, initiatives promoting socialization among people with dementia and activities aimed to carers’ support had to close. This scenario proved to be a great challenge for everyone, including non-profit volunteers organizations as ARAD. We tried to make the best of a bad bargain and kept all our activities going, although at distance, using virtual facilities. Thanks to electronic technology, our psychologists carried on carers’ support through Skype meetings or telephone calls, various WhatsApp groups share daily life events, emotions and practical ideas to overcome this difficult time. ARAD runs two Alzheimer Café in Bologna and one in a nearby town; using virtual meetings all the steps of an usual Café could be maintained: the welcoming greeting, the singing wich helps each participant to introduce him/herself, plays (a modified game of goose where players are asked to perform simple tasks, food games, etc.), performances (pretending to leave by an imaginary train...). Memory training sessions for persons at risk of isolation were issued through videos prepared by our psychologists, while those with manifest cognitive decline could benefit of personalized videos from our Validation Therapy teacher. Psychologists and a professional performing artist guided creative narration and performances by carers who shared their productions on the computer screen. For persons with dementia and for caregivers, physical contact and empathic communication are of paramount importance and lockdown due to Covid-19 pandemia caused overwhelming strain wich, partially and temporarily, has been eased by solutions unthinkable in usual times.

PO1.38. Social media and virtual gathering among persons with dementia and their carers facing Covid-19 outbreak

D’ANASTASIO Clelia1, RIBANI Valeria1, BARBANI Elisa1, QUARTINI Ilaria1, RANÙ Maria1, SALMI Sandra1, ZAMBONELLI Cristina1, ASCOLESE Andrea2

1ARAD-Associazione Ricerca Assistenza Demenze, Bologna, Italy, 2Professional performing artist, Bologna, Italy

Objectives: Acceptance and Commitment Therapy (ACT) is a constructive approach to psychotherapy that focuses on psychological flexibility (PF), improving function and behavior change rather than symptom reduction. Informal caregivers of people with dementia (PWD) often experience challenging situations due to their role and applying ACT may support their coping skills in everyday life. To date, however, the use of ACT approach among this population seems rare. This systematic review will examine the feasibility, clinical effectiveness, quality of evidence, and mechanisms of change in ACT interventions for various informal caregivers populations.

Method/Design: The protocol of this review is registered on Prospero. A systematic search of five online databases was conducted to find studies investigating ACT interventions in informal caregivers. Overall 1670 articles have been identified. Studies will be included when they are (i) published, (ii) written in English, (iii) focused on informal caregivers of adult, and (iv) ACT intervention in any form (e.g. in person, online). The quality of included studies will be determined using the GRADE tool. Results will inform on the context, mechanisms, and outcomes and be synthesized to identify key components.

Discussion: Although study quality may vary, results are expected to inform on the feasibility of ACT and potential benefits for informal caregivers. Special attention will be paid to PF as a mediator of distress, depression, and anxiety. Findings of this study will provide a useful overview of the utility of various ACT interventions that have been conducted for informal caregivers. This knowledge will be beneficial for researchers, clinicians, and policy makers in order to enable the most appropriate ACT intervention for informal caregivers of PWD. An ACT intervention for informal caregivers of PWD will be designed and piloted followingly. Full results will be presented in detail in the conference session.

PO1.39. The potential utility of acceptance and commitment therapy for informal caregivers of people with dementia: a systematic review

ATEFI Golnaz1, ATEFI Golnaz2, BARTELS Sara Laureen2, KILKENS Tessa3, VERHEY Frans4, DE VUGT Marjolijn2

1The University of Maastricht, Maastricht, Netherlands, 2Department of Psychiatry and Neuropsychology and Alzheimer Centre Limburg, School for Mental Health and Neurosciences, Maastricht, Netherlands, 3MET ggz Maastricht, Maastricht, Netherlands

Objectives: Our project n. 760219 (Met and unmet needs of vulnerable older patients receiving healthcare at home and in hospital) was accepted for funding by the Grant Agency of Charles University. It aims to provide a comprehensive overview of the needs of vulnerable older patients and patients with dementia.
Initial deliverables of the project are scoping reviews of self-reported needs of 1) older people in home care; 2) older patients in hospital care; and 3) home dwelling people with dementia. The aim of this presentation is to explore the needs of people living with dementia in acute hospital care.

Methods: A scoping review of the articles published between 2009 and 2019 was carried out using the databases Scopus, Web of science, PsycInfo, ProQuest Central, CINAHL and PubMed to search for relevant articles according to PRISMA guidelines.

Results: The poster will present the results from the scoping review of the needs of people with dementia in acute hospital care. The context and comparison of the previous results of our project will be included.

PO2.2. Caring for people with dementia in perioperative environments: the experiences of healthcare professionals

DIAZ-GIL Alicia¹, APPLETON Jane¹, KOZLOWSKA Olga², PENDLEBURY Sarah²
¹Oxford Brookes University, Oxford, United Kingdom, ²Nuffield Department of Clinical Neurosciences, Oxford, United Kingdom

Background: The increasing prevalence of dementia has an impact on healthcare services, with higher numbers of people diagnosed with dementia undergoing surgical procedures. Perioperative care for patients with dementia represents a challenge for the person with dementia, their family members and healthcare professionals. Previous literature suggests that people with dementia experience higher risk of negative outcomes after a surgical procedure. Exploring the surgical trajectory and identifying the main issues and risks is necessary to start working on solutions.

Aim: To identify the major issues and challenges that healthcare professionals working in perioperative areas experience when caring for people with dementia.

Methods: Participants from four hospitals at the Oxford University Hospitals NHS Trust were recruited. Data was collected using semi-structured face to face interviews. Five participants have been interviewed from a total of sixteen planned participants. Preliminary data was analysed using thematic analysis by Braun and Clarke (2006), with the use of the NVivo 12 software.

Results: Analysis on this preliminary data suggests that perioperative care for people who have dementia could be improved. From the nursing point of view, healthcare professionals reported that their knowledge and training about dementia is very scarce and the majority of them have learned through their clinical experiences. Main issues reported were lack of communication between departments, problems related to pain assessment and difficulties ensuring patient safety while preserving their dignity. From the anaesthetic point of view, issues reported included concerns regarding informed consent for surgery and selecting the most appropriate form of anaesthesia.

Conclusion: Although this research is still in process, these initial results show that current practice needs to evolve to ensure that healthcare professionals are providing the best care for people with dementia during their surgical trajectory. More training is needed for healthcare professionals working in perioperative environments regarding dementia care.

PO2.3. Investigating the association between ward and discharge discussions regarding support needs for people with dementia

BOURKE Lori, MORRIS Aimee
Royal College of Psychiatrists, London, United Kingdom

The National Audit of Dementia (NAD) collects information from general hospitals in England and Wales to evaluate the quality of care provided to people with dementia. For Round 4 of audit (published 2019) hospitals submitted information from the casenotes of 50-100 patients. 9762 casenotes were submitted across 192 hospitals. The team aimed to investigate the association between the ward on which the patient spent the most time and the documentation of discussions with the person with dementia, carer/family member and medical staff regarding support needs at discharge. The audit tool included 4 questions asking about recorded discussions of support needs with: the person with dementia, a carer or family member, a consultant, and members of the multidisciplinary team (MDT). In 28% of casenotes discharge plans were discussed with all 4 groups. This was most commonly discussed with the MDT (85%) and least likely to be discussed with the person with dementia (57%). We calculated a combined average across all four questions which revealed that patients on the care of the elderly ward (COE) were most likely to have involvement (80%) followed by stroke (76%) and orthopaedic (76%). A multiple regression revealed that ward had a significant impact on the presence of these discharge discussions. COE had the largest effect (P< .000) accounting for 73% of the variance. Although the number of casenotes present (R² = .024) and LOS (R² = 0.10) had a significant influence on discharge discussions, this only accounted for a very small amount of variance. These findings highlight initial evidence that the ward on which a patient spent the most time influences whether discussions of support needs are likely to take place at discharge.
A highly regulated industry drives tick-box approaches to learning in dementia care. Resources can be deployed ineffectively, at a high cost without meaningful impact. Barriers such as negative media representations of care work ‘unskilled’ limit opportunities for creative approaches to learning. A different approach is required to deliver sustainable changes in practice, one that recognises the central role the care worker has in designing and leading their own learning journey.

The technological explosion driven by the pandemic has opened up new possibilities for utilising technology to deliver programmes which drive behavioural changes front line. Examples of barriers removed by the pandemic are greater digital capability, opportunities for collaboration and more control for the learning to navigate and contribute to their own learning journey.

My organisation has been developing infographics in dementia care for the past ten years, as part of a broader strategy to utilise creative approaches to learning. During this time testing and measuring different approaches to dementia education to identify those that are most impactful. This has led to important insights around effective practice and highlighted the role of training services bringing to bridging academia and practice. Our infographics are designed to start conversations in busy environments, make complex research findings accessible to front line practice that act as important memory aids at the point of practice.

However, infographics are only part of the strategy, specific activities before, during and after training are required to improve dementia care practice. Two years ago, I started by a professional doctorate at Stirling University where I am hoping to explore these possibilities, now with the aid of a community that is much more digitally able and aware. In my research, I am hoping to explore the factors that support the development of compassionate, capable and confident workforces.

Background: Researchers, policymakers, and health care professionals often stress the importance of early dementia diagnosis in a mild stage of the disease. However, there is a lack of consensus on the advantages and disadvantages of an early dementia diagnosis. As a consequence, the debate is shifting away from advantages of an early diagnosis in favor of a timely diagnosis. A timely diagnosis implies that a diagnostic process is initiated at the right time for the person with memory complaints and their significant other(s) so as to meet their preferences, needs and expectations.

Objectives: An integrative review will be conducted to explore and map the available scientific evidence about the preferences of people with memory complaints and their significant others regarding a timely diagnostic process for dementia and decision-making in that process.

Methods: The scientific databases PubMed, PsycINFO, CINAHL, Web of Science and Embase will be systematically searched for studies on dementia diagnosis preferences published between January 2010 and June 2020. Methodological quality of the included studies will be assessed with the Mixed Method Appraisal Tool.

Conclusions: It is anticipated that this integrative review provides important input for optimizing clinical guidelines and could facilitate a more-in depth discussion in the consulting room of the general practitioner (GP) about starting a diagnostic process. Moreover, results could be used to support the development of patient decision aids that support decision making about a dementia diagnosis in general practice. Results are expected by October 2020 and will give an overview of the existing evidence in this field.
PO3.7. Systematic mapping review on factors impacting the pathway from health to dementia

LENART Marta1, LENART Marta1, ŁUC Mateusz1, PAWŁOWSKI Marcin1, SZCZEŚNIAK Dorota1, SEIFERT Imke2, WIEGELMANN Henrik2, GERHARDUS Anggar2, WOLF-OSTERMANN Karin1, ROUWETTE Etienne3, RYMASZEWSKA Joanna1

1Department of Psychiatry, Wroclaw Medical University, Wroclaw, Poland, 2Department of Human and Health Sciences, University of Bremen, Bremen, Germany, 3Radboud University Medical Center, Nijmegen, Netherlands

The multitude of available dementia studies and their wide scope requires systematic data synthesis in order to be able to contribute to the knowledge of the complexity of its pathogenesis through an integrated approach. The systematic review aims to provide comprehensive maps of evidence for all factors that affect cognitive functions in the context of the development and course of dementia. In addition, it highlights the role of social aspects and identifies knowledge gaps in dementia research.

The review is a part of JPND project Social Health And Reserve in the Dementia patient journey (SHARED). Five databases: Medline, PsycINFO, CINAHL Complete, Cochrane and Epistemonikos were searched for systematic reviews and meta-analyses from 2009 to 2019. All abstracts and full texts were independently screened and reviewed. Methodology appraisal was conducted using a standard checklist.

Among 310 included papers, 613 factors were grouped into 7 categories with 61 subcategories: personal (22), environmental (30), socioeconomic (40), psychological (44), social (50), lifestyle (152) and biomedical (275). Majority of the factors were significantly associated with cognitive functions or dementia (62% with negative and 20% with positive impact), in 3.5% of cases no influence has been proved and for 14% this effect remained unclear.

The results indicate the dominance of research carried in European countries (36%) and in China (29%), related to biology and medicine (45%) and health behaviour (24.8%). Identifying social factors in the trajectory of cognitive decline suggests their positive role against cognitive decline and dementia by reducing the risk or delaying the onset.

Obtained data indicate the lack of studies reporting results on cognitively healthy individuals, protective factors, cognitive reserve, and the need for further research on modifiable factors, such as social and psychological aspects.

PO3.8. Assessing knowledge & perceptions towards people with Alzheimer’s disease among employees of a pharma company

GARCIA ARCELAY Elena1, GARCIA RIBAS Guillermo2, MONTOYA Alonso2, MAURÍÑO Jorge3

1Roche Farma, Madrid, Spain, 2Hospital Ramón y Cajal, Madrid, Spain, 3Hoffmann-La Roche Limited, Mississauga, Ontario, Canada

Objectives: Increased knowledge about an illness may help identifying the disorder to seek for an earlier intervention and appropriate healthcare. However, information about how the public knows about its risk factors, diagnosis, course, and management are limited. The main aim of this study was to assess knowledge and perceptions about AD from the caregiver/non-caregiver perspectives using a standardized battery of questionnaires.

Methods: A non-interventional, cross-sectional, anonymized web-based study was conducted among employees of Roche Spain. Participants answered sociodemographic questions and the Alzheimer’s Disease Knowledge Scale (ADKS). Caregivers answered questions related to their personal experience caring for someone with AD and fulfilled the Satisfaction with Life Scale, Beck Depression Inventory-Fast Screen, and the disruption dimension of the Revised Memory and Behavior Problems Checklist.

Results: A total of 447 subjects participated (19% of the total of employees). 63% were between 30-50 years old, 65% were female, and 83% had bachelor or master degrees. Forty-two (9%) of participants were caregivers, mainly of moderate to severe dementia subjects. Overall knowledge about AD was moderate (mean ADKS score = 21.2 ± 2.8 [71% of correct answers]). Risk factors and caregiving were the lowest scores domains (correct answers percentage = 59% and 63%, respectively). Mean ADKS score was significantly higher in participants caring people with AD compared with non-caregivers (22.1 ± 2.9 and 21.0 ± 2.8; p=0.02, respectively). The scores were not influenced by age, sex, or educational level. Most caregivers were satisfied with life (mean SWLS score = 26.8 ± 5.6) showing a low impact reaction to disruptive behaviors (mean RMBPC score = 9.1 ± 9.1). Six of them (14%) were scored as depressed.

Conclusions: There is a continuing need to improve the understanding of AD to fulfill the gaps in knowledge of AD, even in a population working in healthcare with a high level of education.

PO3.9. Withdrawn

PO3.10. Ethical issues considering Alzheimer’s disease. Diagnosis disclosure in the patient/family/caregiver relationship

NICULESCU Mihaela Cosmina1, IOANCIO Ioana1, DOSCAN Ana Maria1, RASUCEANU-DIACONESCU Alexandra1, MAXIM Tatiana1, SPIRU Luiza1-2
Background: In the context of population aging, mankind is confronted with numerous challenges of the so-called “Alzheimer Crisis”. Diagnostic disclosure is a shock to patients and their families, who fear their own possible proneness to this illness. Moreover, because of reasons such as accessibility to medical services or lack of medical education in the general population, more and more of them come to the physician and are diagnosed beyond mild stages. In addition, the current lack of drugs to improve the disease, leads to distrust and reluctance to recommended therapeutic protocols. We are often confronted with various problems in our Memory Clinic in Bucharest, related to illness acceptance, understanding, dark feelings and projections, treatment mistrust and non-compliance of the patient, as well as stumbles in the necessary empathy/support of their formal/informal caregivers.

Material and methods: We designed and operated two simple (Yes/No) questionnaires: (1) a questionnaire for diagnosticians and (2) a questionnaire for patient’s relative(s)/caregiver(s). We applied them on our diagnosticians team and on 140 relatives/caregivers dealing with Alzheimer’s Disease patients. The dialogue with the questioned doctors, relatives/caregivers was simple and concise, adapted to the given level of their education. The answers were processed as percentage of positive/negative options for every question and group of respondents.

Results & conclusions: Alzheimer’s Disease diagnostic disclosure is not only the first but also a crucial step in approaching Alzheimer’s Disease patients. Although it is a challenging moment for both healthcare professionals, patients and their relatives/caregivers, the diagnostic disclosure of Alzheimer’s Disease represents a beneficial turntable for a long-lasting period of concerns and defenselessness of this frail patients who need both professional support from the multidisciplinary team and empathy, patience and support from those who matter the most to them (relatives, formal/informal caregivers), if carefully, empathetic and professionally done in a proper environment.

PO3.11. What to eat and what nutritional supplements intake you need to reduce your risk of Alzheimer’s disease

IVANOV Bogdan
Smart EpiGenetX, Voluntari, Romania

NutriCare.Life precision nutrition digital platform

The risk of cognitive impairment, Alzheimer’s disease, and dementia can be reduced. There are different factors that might reduce these risks and keep the brain healthy. One of them is proper nutrition.

NutriCare.Life use the latest research in microbiology, genetics and nutrition to provide personalized insights to encourage healthier eating behaviours. Our patent-pending technology use self-reported eating habit to provide ultra-personalized recommendations on the ideal intake of food, vitamins and minerals.

To increase nutrition assessment accuracy users can benefit from at-home genetic, blood and urine tests. Our customers receive a comprehensive list of foods that best suit their nutritional requirements and personalized nutritional supplements at their home.

Micronutrients associated with dementia / Alzheimer’s / cognitive decline:
- Choline: 21y follow up. 28% less incident dementia in 4th Q vs 1st Q (Ylilauri et al, 2019)
- DHA & EPA: lower risk of AD (not in short studies) (Gillette-Guyonnet 2013, Barberger-Gateau 2011, 2007)
- Vitamin E & C: reduced risk of AD (Zandi 2004). Not in all studies.
- Vitamin D: risk factor for AD (reduced plasma concentrations) (Grant 2016)
- Vitamin A & Bs: risk factors for geriatric cognitive impairment (plasma levels) (Raszewski 2016, Chen 2015)
- Iron: altered homeostasis in neurodegenerative disorders (rev Belaidi 2015)

Eating right, taking the proper supplements, you can prevent Alzheimer disease, live longer and healthier.

PO3.12. Withdrawn

PO3.13. From air pollution to brain pollution - novel biomarkers to unravel the link of air pollution and Alzheimer's disease

CHEW Sweelin1, DINNYÉS András2, GIUGNO Rosalba3, IKRAM Arfan4, MALM Tarja1, OUDIN Anna5, SANDSTRÖM Thomas8, TOPINKA Jan6, ZENG Xiaowen7, KANNINEN Katja1

1University of Eastern Finland, Kuopio, Finland, 2Biotalentum Ltd, Gödöllö, Hungary, 3University of Verona, Verona, Italy, 4Erasmus MC, Rotterdam, Netherlands, 5University of Umeå, Umeå, Sweden, 6Institute of Experimental Medicine, Czech Academy of Science, Prague, Czech Republic, 7Sun Yat-sen University, Guangzhou, China

Despite decades of Alzheimer’s disease (AD) research, the molecular pathophysiology of the disease remains elusive, and treatment strategies are debated. Little attention is paid to the involvement of environmental factors, which epidemiological studies reported to strongly influence AD development. Air pollution, a major public health issue, is an important, global concern. Evidence from epidemiological and controlled animal studies shows that exposure to air pollutants also impairs the brain. Furthermore, living
in polluted areas is associated with exacerbated cognitive dysfunction and AD although information on air pollutant effects on brain health is scarce. Importantly, there are no biomarkers for air pollution and AD risk prediction, which hinders identifying and stratifying individuals at-risk for harmful air pollution effects.

Drawing upon unique expertise and cutting-edge methods, the ADAIR consortium engages multiple disciplines in neurobiology, epidemiology, clinical science, environmental science and data science and is poised to provide crucial mechanistic insight on air pollutant effects on the brain and discover biomarkers for air pollution and AD risk prediction. ADAIR applies a precision medicine approach to stratify individuals to subgroups for risk estimation and future AD prevention, ultimately aiming to target air pollutant-induced processes in individuals who can most benefit from them.

We investigate the novel hypothesis that pollutant exposure environment alters cellular mechanisms and functions in the brain, resulting in the expression of measurable biomarkers. By identifying biomarkers, individuals with increased AD risk can be stratified prior to the disease onset and preventive measures can be targeted to the specific at-risk populations to be most effective. ADAIR address a major societal challenge with wide health-related, environmental, economic, scientific, social, and political impact. The goal is to develop strategies for early identification of people at risk of AD, and to discover novel targets for preventive strategies to reduce the healthcare and socio-economic burden of AD.

PO3.14. Dementias Platform UK (DPUK): facilitating multi-modal digital data access for dementias research

BAUERMEISTER Sarah, GALLACHER John
University of Oxford and Dementias Platform UK (DPUK), Oxford, United Kingdom

Dementias Platform UK (DPUK) is a £53M public-private partnership established by the MRC to provide free access to large-scale cohort data and accelerate the research and discovery of new treatments for dementia. DPUK facilitates multi-modal data access to 42 cohorts across 3.4M individuals within a remote access data repository, the DPUK Data Portal. Globally, there is the need for a solution to manage, process and curate data which is secure, robust, persistent and auditable. DPUK meets this need by managing datasets that are increasingly large, complex, sensitive and are decreasingly feasible to download, transfer and store. DPUK invests in standardisation of cohort data for cross-cohort analysis with C-Surv, the DPUK data curation programme. We present the latest data discovery and curation developments for the DPUK Data Portal and, how digital innovation is enhancing cross-cohort and multi-modal analysis for dementias research.

PO3.15. Professional stress – a major risk factor in Alzheimer’s disease

DOSCAN Ana Maria, SPIRU Luiza, IOANCIO Ioana, NICULESCU Mihaela Cosmina
"Elias" Emergency University Hospital – Clinical Department of Geriatrics, Gerontology and Old Age Psychiatry, Bucharest, Romania

Introduction: Early brain aging (objectified by decreasing the age of onset of neurocognitive impairment) in the 35-50 age segment has become a major concern for longevity medicine. Hence the need to extensively investigate chronic occupational stress and its effects on human brain, especially when acting as a risk factor for early Alzheimer’s disease.

Aims: Preventive diagnosis of stress vulnerability, identification of demands that may exceed the individual’s ability to respond effectively, quantification and objectification of stress, will help the deceleration of early brain aging process.

Methods: The study is designed to evaluate professional chronic stress that includes: history of stress in patients’ life, neurocognitive stress scales evaluation, biological evaluation of stress hormones - urinary determination of serotonin, melatonin, adrenalin / noradrenalin, dopamine and salivary cortisol and measurement of heart rate variability.

Results: Our study results, based on the evaluation of 150 patients aged between 35-50 years old, who work in stressful environment, show the link between elevated cortisol levels and the occurrence of clinical manifestations of neurocognitive impairment in the context of persistent occupational stress, and also the presence of depressive disorder in patients’ life history, in the context of changes in biological stress markers.

Conclusions: Persistent professional stress can cause changes in the body’s normal defense response to stress factors. Early identification of occupational stressors, clinical and biological knowledge of stress as well as the development of preventive and personalized measures, may define a future approach in the context of preventing stress induced pathologies like depression and anxiety, but also neurocognitive disorders (from mild cognitive impairment to early Alzheimer’s disease).

PO3.16. The development of a microsimulation model to predict the future burden of dementia

BRÜCK Chiara1, WOLTERS Frank2, IKRAM Arfan2, DE KOK Inge1
1Department of Public Health, Erasmus MC, Rotterdam, Netherlands, 2Department of Epidemiology, Erasmus MC, Rotterdam, Netherlands

Background: Microsimulation models are a useful tool in dementia research as they can evaluate uncertainties about the development of dementia, synthesise complex information, take trends in risk factors into account, and estimate long-term and population wide effects of (hypothetical) interventions.
Methods: Based on the well-known Microsimulation Screening Analysis (MISCAN) model from cancer research, we developed a dementia microsimulation model. It synthesises incidence data from the Rotterdam Study (Ikram et al., 2017) with severity stage duration estimates from the literature (Vermunt et al., 2019). The onset of mild cognitive impairment (MCI) was calibrated on observed dementia incidence rates by age from the Rotterdam Study. The model simulates the life histories of individuals, each of whom can develop MCI which can then progress to mild and moderate/severe dementia and finally death. The number of dementia cases, dementia deaths, (quality adjusted) life years of patients and caregivers, and costs can be evaluated by age and gender. Finally, the model can estimate the effect of interventions on the life histories and subsequently the outcome measures.

Result: The MISCAN-Dementia model consists of three modules: a demography module, a natural history module, and a screening module. Given this structure, the model can be used to evaluate long-term benefits and harms of important interventions at different disease stages: 1) changes in risk factors; 2) earlier detection and treatment by population screening; and 3) care and cure. We were able to fit the observed dementia incidence in The Netherlands. We will present the structure of the model and first prediction results.

Conclusion: The dementia microsimulation model developed in this study predicts how the burden of dementia will develop over the coming decades, including incidence, mortality, costs, and quality of life. Modelling the effect of interventions on a population level will provide essential information for policy makers and researchers.

PO3.17. COVID-19 era: new technological strategies to manage Behavioral and Psychological Symptoms in Dementia (BPSD)

BAZZANO Salvatore, FORMILAN Marino, VERONESE Nicola, CESTER Alberto, BOLZETTA Francesco, MASELLI monica, CHIAROMANNI Federica, BUSONERA Flavio, BONOMETTO Pietro, ROMANO Antonietta

AULSS 3 Serenissima, italiana, Italy

Introduction: The COVID-19 pandemic has recently changed the interaction with healthcare users. Current challenge of healthcare is to provide services for COVID-19 disease but also for acute and chronic diseases. While the COVID-19 evolves, telemedicine has become an important tool for patients care. Telehealth could be particularly useful in the group of older patients affected by dementia. In this group, telemedicine may help to keep patients safe and to identify/treat Behavioral and Psychological Symptoms of Dementia (BPSD). The aim of this project is to use a telemedicine program to manage older patients with BPSD.

Materials and methods: Two rooms with a continuous recording video surveillance are available in our geriatric ward. This system allows to monitor older patients with BPSD. Based on this experience, we are developing a new model of Cognitive Disorders Clinic, with patient monitoring and management based on telemedicine. The model includes an online platform and an app that allow the caregivers to share clinical and video information with clinicians. This service could identify BPSD and other disorders, enabling faster and more effective remote management. The Maladaptive Behavior Scale (MABS) will be used for a quantitative measurement of behavioral disorders.

Expected results: The idea of this project is to develop a telehealth program that may reduce the risk of infection of patients and health personnel and provides a highly effective remote monitoring system for disorders correlated to dementia. This could improve the patient’s quality of life, optimize the management of BPSD, reduce the waiting list for visits and, at the end, improve the quality of health services.

Conclusions: In the COVID-19 period, the telehealth services could be particularly useful in older patients with dementia and BPSD.

PO3.18. Should doctors offer biomarker testing to those with cognitive complaints who are afraid to develop Alzheimer’s dementia?

SMEDINGA Marthe, RICHARD Edo

RadboudUMC, Netherlands

An increasing number of people seek medical attention for mild cognitive symptoms at older age, worried that they might develop Alzheimer’s disease. Some clinical practice guidelines suggest offering biomarker testing in such cases, using a brain scan or a lumbar puncture, to improve diagnostic certainty about Alzheimer’s disease and enable an earlier diagnosis. Other clinical guidelines, however, explicitly refrain from suggesting biomarker testing because the tests lack clinical validity. There is also no effective treatment for Alzheimer’s disease.

The debate on whether Alzheimer biomarker testing should be offered in clinical practice is currently polarised; advocates and opponents tend to focus on their own line of arguments. In this paper, we show how the method of reflective equilibrium (RE) can be used to systematically weigh the relevant arguments on both sides of the debate.

In the tradition of RE, we reflect upon arguments in favour of and against biomarker testing in light of their coherence with other argumentative elements, including relevant facts (e.g. on the clinical validity of the test), ethical principles and theories on societal ideals or relevant concepts, such as autonomy and over-
medicalisation. Rather than debating within a relatively medical-technical scope, the method of RE thus forces us to adopt a wide societal perspective. Furthermore, through the systematization of the argument, those who disagree with our conclusion can point out which arguments they find missing, which ones they question and those that they agree with. In this way, this paper aims to constructively nuance and advance the debate on the desirability of Alzheimer biomarker testing in clinical practice.

PO3.19. Remote assessment of Alzheimer’s Disease: the RADAR-AD study
MUURLING Marijn, DE BOER Casper, VISSER Pieter Jelle, RADAR-AD Consortium
Amsterdam UMC, Netherlands

Introduction: Functional and cognitive decline in Alzheimer’s Disease (AD) is typically measured using single time-point subjective rating scales, which rely on direct observation or (caregiver) recall. Remote Monitoring Technologies (RMTs), such as smartphone applications and wearables can change these periodic subjective assessments to more frequent, or even continuous objective monitoring. The aim of the RADAR-AD study is to assess the accuracy and validity of RMTs in measuring functional and cognitive decline in a real-world environment across pre-clinical-to-moderate stages of AD compared to standard clinical rating scales.

Methods: We will include participants (n=220) with preclinical AD, prodromal AD, mild-to-moderate AD and healthy controls from clinical sites equally distributed over 13 European countries. Participants will undergo extensive neuropsychological testing and physical examination. The RMT assessments, performed over an 8-week period, include walk tests, financial management tasks, an augmented reality game, two activity trackers measuring activity and sleep patterns, and two smartphone applications installed on the participants’ phone assessing cognition, phone usage and mobility. The primary outcome of this study is the difference in functional domain profiles assessed using RMTs between the four study groups. Additionally, each RMT outcome will be compared to a standard clinical test which measures the same functional or cognitive domain. Data collection and privacy are important aspects of the project, which will be managed using the RADAR-base data platform running on specifically designed biomedical research computing infrastructure.

Conclusion: Our study is well placed to evaluate the clinical utility of RMT assessments. Leveraging modern-day technology may deliver new and improved methods for accurately monitoring functional decline in all stages of AD. It is greatly anticipated that these methods could lead to objective and real-life functional endpoints with increased sensitivity in clinical trials. The first inclusions show promising results regarding appliance and usability.

PO4. People

PO4.1. Home-care workers experiences of looking after people with dementia: a qualitative interview study
BACKHOUSE Tamara, RUSTON Annmarie
University of East Anglia, Norwich, United Kingdom

Background: Home-care workers are increasingly caring for clients with dementia. Workers are usually low paid, have limited dementia training, and are working on their own. Little is known about their experiences of providing day-to-day care to people with dementia.

Aim: To explore the understanding and experiences of home-care workers when providing care to people with dementia.

Methods: We conducted 17 semi-structured interviews with home care workers in one locality in the East of England. Interviews were audio-recorded and transcribed verbatim. Analysis was inductive and thematic.

Results: Two key themes were present in the data: ‘identifying and managing risk’ and ‘overcoming challenges in care by bringing the person along’. Home-care workers were aware of multiple potential risks to clients with dementia such as getting lost, fires or falling during the time between care calls. Risks to the home-care workers themselves included clients’ aggressive behaviours and working on their own. Home-care staff worked hard to manage these risks by drawing on their own experiences, their training and the wider team. Challenges in care included time constraints, clients’ dementia-related characteristics, refusals of care, and bearing responsibility. To bring the person along on the caring journey workers enacted a caring relationship, thought about their approach, and used distraction and different communication strategies.

Conclusion: Home care workers encountered multiple challenges when looking after people with dementia. Often they were on their own dealing with uncertain circumstances and carrying the responsibility for care decisions. Our findings showed that home-care workers had a good understanding of their role, and the risks and challenges they faced. They were resourceful, considerate, and used multiple approaches to cope and provide necessary care.
PO4.2. Persons with dementia and informal caregivers prioritizing care: a focus group study

WAMMES Joost1, LABRIE Nanon2, AGOGO George3, MONIN Joan4, DE BEKKER-GROB Esther5, MACNEIL-VROOMEN Janet1

1Amsterdam University Medical Centres, Amsterdam, Netherlands, 2Athena Institute, Vrije Universiteit Amsterdam, Netherlands, 3Center for Disease Control and Prevention (CDC), Kenya, 4Yale School of Public Health, USA, 5Erasmus University Rotterdam, Netherlands

Introduction: More persons with dementia are residing in the community as many countries shift from residential care to home and community care. Although there are many forms of care and support available to avoid crisis situations and prolong community living, it remains unclear how these are valued by community-dwelling persons with dementia and their informal caregivers. Consolidating perspectives of persons with dementia and informal caregivers on care characteristics is a vital step in valuing care services. This study aims to prioritize care characteristics for community-dwelling persons with dementia and informal caregivers.

Methods: Six focus groups were conducted in the Netherlands with persons with dementia (n=23) and informal caregivers (n=20), including a ranking exercise prioritizing seven care and support characteristics from “most important” to “least important”, followed by a discussion about the prioritization. Audio recordings were transcribed and analyzed using thematic analysis.

Results: The ranking exercise and discussion showed that persons with dementia favored In-home care, Help with daily activities, and Social activities, while informal caregivers favored Social activities, Information about dementia, Navigating the healthcare system, and Emotional support.

Discussion: This study created a method to capture persons with dementia and informal caregivers care priorities. Persons with dementia prioritized day-to-day activities, while informal caregivers preferred assistance with organizing care and coping with caregiving.

PO4.3. Developing guidelines for the involvement of people with dementia in policy, advisory, consultation and conference activities

KEOGH Fiona1, WORKING GROUP Irish Dementia2, WHELAN Clodagh2

1NUI Galway, Galway, Ireland, 2Alzheimer Society of Ireland, National, Ireland

There is an increasing desire to include people with dementia in work such as policy formulation and policy implementation and to have people with dementia make contributions to meetings and conferences. However, there is a lack of guidance on how best to do this. Our three organisations (the Irish Dementia Working Group (IDWG), the Alzheimer Society of Ireland and the Centre for Economic and Social Research on Dementia) have worked together for several years in promoting the involvement of people with dementia in decision-making and we wanted to bring our experience together into a set of practical, detailed and clear guidance.

Six members of the IDWG discussed the main points they wanted to be included in the guidelines and the messages they wanted to communicate. Four people who support people with dementia were also consulted on the barriers and facilitators for the involvement of people with dementia. We also consulted guidance documents prepared by the Dementia Engagement and Empowerment Project (DEEP).

The following underpinning principles were identified to guide the process of involving people with dementia: Give the person a voice; See the person; Emphasise the strengths and abilities of each person; Participation is a human right; Be flexible; Respond to each person as an individual; Never judge a book by its cover; and Safeguarding.

To guide practice, ten guidelines were developed: Interaction; Communication; Providing information; Venue; Travel; Consent; Support; Recognition and acknowledgement; Payment and expenses; and Different types of involvement.

The cover image for the document was designed by IDWG member Marguerite Keating. Marguerite used the forget-me-not flower and worker bees. The bees symbolise the members of the Irish Dementia Working Group.

The guidelines are available for any group or organisation who want to work with the IDWG and are available online for anyone to read.

PO4.4. Creating enabling environments in a library and in the community – the project “The Dementia-friendly library Wiener Neustadt”

TATZER Verena1, PLUNGER Petra2, ULLMER Rebecca3, FELLINGER Ulrike1, REITINGER Elisabeth2, FELLINGER Ulrike2, HEIMERL Katharina2

1University of Applied Sciences Wiener Neustadt, Wiener Neustadt, Austria, 2University of Vienna, Vienna, Austria, 3Central Library, Wiener Neustadt, Austria

People with dementia and their caregivers may experience restrictions in social participation. There is little knowledge about how non-health organizations in a city can contribute to enhanced health literacy and foster social participation of people living with dementia and their caregivers. Public organizations need to provide good health information to support citizens and improve their health literacy when living with cognitive impairment. Libraries are spaces of education and learning and thus have an important function in a city. They offer possibilities to participate in public life but can also provide information about themes related to living with neurocognitive disorders and offer space for connection and collaboration. We aim
to create a dementia-friendly library in collaboration with two other organizations in the community: the information service point of the city hall and a museum. All three organizations are important public institutions in the city. The aims of the project are to foster social participation of people with dementia and their caregivers as well as to contribute to de-stigmatization and enhance health-literacy in the public. Using a participatory health research design based on needs assessments with management and staff from all three organizations will ensure sustainability. All interventions are developed collaboratively in the steering group with the local self-help group Alzheimer Austria including the perspective of caregivers of people with dementia and an activist living with cognitive impairment as well as the management of all three organizations. We will present findings from the needs assessment including online focus groups with staff, telephone interviews with caregivers and discuss the impact of the Covid-19 pandemic on the needs assessment.

PO4.5. Well-being from a migration perspective of older persons with an Indonesian background in the Netherlands

Kharismayekti Manik¹, Caljouw Monique²
¹Stichting Alzheimer Indonesia Nederlands, Zoetermeer, Netherlands, ²Leiden University Medical Centre, Leiden, Netherlands

Background: The migration of people from Indonesia to The Netherlands occurred after World War II. The first and second generation of the Indonesian migrants were included to the total older population in the Netherlands. Their presence, with their influence of Asian culture creates challenges for the health care organizations in the Netherlands.

Objective: This study aims to explore the important aspects of well-being of older migrants with Indonesian background’s and their perspectives on ageing.

Method: This is a qualitative study with a semi-structured, in-depth interview among 11 older persons with an Indonesian background in the senior residential PINS, the Garantwoning and nursing home Waterhof between May and June 2019. A modified version of grounded theory approach that combines the inductive and abduction approaches was chosen to analyse the data.

Results: All participants were considered as the first generation of Indonesian migrants who left Indonesia between year 1945 and 1962. The participants mentioned that social contact, autonomy and functional health were important aspect of their well-being. Positive behaviour and social support which are covered within their cultural identities, such as: religious beliefs, meals and cultural activities, were needed to support them to stay longer in the community.

Conclusion: This study enriches the insight about older migrants with an Indonesian background, and generates a combination of scientific literature and qualitative research on cultural-sensitive approach in improving well-being of older migrants. Further research about well-being of other groups of older migrants with an Indonesian background and a nursing home which offers culturally specific care, are needed.

PO4.6. Together in care program

RuanoVA Lucía, Rodríguez Juan Carlos
Federación Alzheimer Galicia, Santiago de compostela, Spain

Introduction: In Galicia approximately 70,000 people with dementia or cognitive impairment reside. In the field of care for people with dementia, demographic data are of great importance, firstly, because age is the main risk factor for the onset of dementia and secondly, because the characteristics of dementias involve resources of proximity and family involvement.

Overall objective: Improve the quality of life of dependent care families affected by Alzheimer’s and other dementias.

Specific objectives: 1. Bring the concept of dementia closer, as well as the resources and services available to those areas where local resources are not adequate
2. Conduct training courses for non-professional caregivers of people with dependency affected by Alzheimer’s and other dementias.
3. Conduct home care application workshops

Material and method: The “Together in care” program is being carried out from 2011 to 2019 (with the exception of 2014). In order for participation to continue, material adapted to the needs of each locality was elaborated and designed, taking into account characteristics such as: rural / urban, population, resources, local services... For all the actions, professionals specialized in Alzheimer's were used. and other dementias, closer to the place of formative action and aware of the reality of that environment.

Results
1. Number of training actions carried out: 113
2. Participants of the training actions: 1,930
3. Assessment of the training action: 4.7 out of 5

Conclusions: Thanks to the performance of this type of actions, groups of relatives of people with dementia were created, where later support and care services were developed for people with dementia and their families, carried out by the reference associations.
PO4.7. Withdrawn
PO4.8. Withdrawn
PO4.9. Carers’ Academy
HOLLAND Susan¹, TONER Alison²
¹NHS Ayrshire and Arran, Kilmarnock, United Kingdom, ²University of the West of Scotland, Ayr, United Kingdom

Background: With a growing reliance on family members to support the holistic care needs of relatives living with dementia at all stages of the disease trajectory, the need for integrated programmes of family carer education which incorporate practical skills based learning has arguably never been greater. However, no such learning programmes were found within Scotland, prior to the establishment of the Carers’ Academy.

Aim: To provide a state-of-the-art practical skills-based learning and information programme to support and sustain family caring of a relative living with dementia.

Objectives: Facilitate opportunities for peer-to-peer learning.
Develop practical skills in the fundamentals of care and caring.
Enhance knowledge and understanding of the effects of dementia.

Participants/methods: The development of the Carers’ Academy has been informed by the knowledge and expertise of family carers of people living with dementia. The programme is facilitated within university settings, by core teams of academics and health and social care practitioners. The programme is designed to be responsive to the needs of family carers of people with dementia living within Scotland, irrespective of the stage/type of their relative’s dementia condition.

Participants are able to access a 1-day bespoke learning programme and a follow-up monthly schedule of skills workshops. Learning is supported using the Care Empathia framework.

Key findings: Feedback indicates positive outcomes in relation to four key interlinking areas:
Planning for existing and future care needs
Easing feelings of guilt, isolation and loneliness
Increasing levels of understanding and empathy
Enhancing levels of confidence in care delivery

Conclusions: The Carer’s Academy programme can have immediate health and well-being benefits to people with dementia and their family carers and our health and social care systems. In the longer term it can help to sustain family caring of a relative living with dementia.

PO4.10. Adapting a psycho-educative intervention to facilitate the participation of informal caregivers
KIPFER Stephanie, PIHET Sandrine
HES-SO: University of Applied Sciences and Arts Western Switzerland, School of Health Sciences, Fribourg, Fribourg, Switzerland

Introduction: The intervention «Learning to feel better and help better» (LFBHB) aims at empowering informal caregivers of a person with dementia (IC-D) to cope with the daily stress of dementia caregiving. This group intervention of 15 weekly sessions of 2 hours each was originally developed and tested with a randomized controlled trial in Canada. It has then been pilot tested in Switzerland within a one group pre-post design, showing substantial improvements in burden, psychological distress and self-efficacy. However, mobilizing IC-D to participate was a challenge. Our project aimed at identifying barriers and facilitators for participation and at adapting the intervention accordingly.

Method: Data on the recruitment process were collected in semi-structured interviews with 15 recruiters from ten organizations, and submitted to an inductive content analysis to identify how the intervention could be adapted. The adaptation was conducted with a participatory approach, including former participants in the LFBHB intervention and representatives of four organizations working with IC-D.

Results: Core barriers for participation were time investment and organization burden due to the length of the intervention, as well as the limited time and knowledge of recruiters. To facilitate recruitment, a film was created to present the intervention, including stories of former participants. The duration of the intervention was reduced to 7 sessions of 3 hours each. Films were created to shorten and standardize information provision, and to facilitate knowledge transfer through role models (examples of former participants). The adapted LFBHB version has now been conducted with four groups of IC-D with similar effects on their quality of life compared to the original intervention.

Conclusion: Including in the adaptation process both IC-D and professionals supporting IC-D fostered a better fit of the intervention to the resources of IC-D, achieving similar effects despite reduced duration.
PO4.11. Withdrawn

PO4.12. We are still together - adapting the activities and services during pandemic

KRIVEC David, L. ZLOBEC Štefanija, GLIŠOVIĆ KRIVEC Špela, BASTARDA Maša, KEČKEŠ Polona, FRECE Patricija
Spominčica - Alzheimer Slovenija, Ljubljana, Slovenia

Persons with dementia and their carers experienced higher social exclusion increased during COVID-19 lockdown, they were left alone and in stress. Carers needed enhanced psychosocial support to maintain hope and endurance. Our association quickly adapted to the new situation, since personal activities were not possible, and strengthened telephone and online counselling. We have used different ways of informing our users: website, social networks, information materials, media articles and online interviews.

The most important and urgent task was to provide information to families on how to adapt. We have published daily advice, guided activities for structuring the day of persons with dementia and ideas for activities at home on our website and social media. We have produced and published a series of leaflets with dementia friendly design (For relatives who have person with dementia in a nursing home, For relatives who have person with dementia at home, How to talk to a person with dementia during epidemic, How to help a person with dementia who lives alone, Wandering and COVID-19…). The leaflets were also shared through communication channels of nursing homes, local communities, Social chamber, Medical Chamber and Ministry for Social Affairs. If carers or persons with dementia needed advice, support, or resolving other dilemmas, a counseling person was available on the helpline every day, including weekends and also via e-mail. To overcome the barriers in access to treatment related information, we have involved experts from the field of Neurology, Psychiatry and Social care in the counselling helpline.

In April we started a survey between members: persons with dementia, their carers, workers in nursing homes and social workers. The aim was to get the insight in how people fell, miss, and what services they have lack because COVID-19. Based on the survey we will adapt our activities and address the policymakers.

PO4.13. Creating a user touchscreen tablets guide for and with people with dementia

MABIRE Jean-Bernard1, PALMIER Cécilia2, CHARRAS Kevin1
1Fondation Médéric Alzheimer, Paris, France, 2Institut de Psychologie - Université de Paris, Boulogne-Billancourt, France

Introduction: Learning and independent use of touchscreen devices can reveal difficult for people with dementia. In a previous study aimed at raising awareness on the uses of touchscreen tablets, some participants expressed the need to have a guide to help them use the tablets alone. Therefore, we collectively decided to create a practical guide for and with people with dementia according to their needs and difficulties towards this technological tool.

Methods: Eight people with dementia attending a day care centre were involved in this project. A focus group was conducted on the need and the content, and appearance of the guide. Then, an observation was undertaken to objectively identify difficulties for using tablets. Data were coded and analyzed to identify themes according to linguistic and extralinguistic evidence contained in the transcription of interviews and observation reports.

Results: The needs expressed by participants concerned common applications such as searching the Internet, watching videos, calling relatives using videoconference. Main difficulties observed for the use of tablets were: to turn on the tablet, to surf the Internet and to manage notifications. To alleviate these difficulties, the guide describes the gestures required to accomplish an action with picture and short sentences and explains the usefulness of the application.

Conclusion: The covid-19 outbreak has not allowed us yet to evaluate this first version with the participants involved in the project and with other people with dementia. This evaluation will ensure that the guide is dementia friendly and that it does not create additional difficulties. If such observations were made, the guide will be modified accordingly and then again validated by participants.

PO4.14. Encourage in life

TOEBES Teun
Teun en toeverlaat foundation, BEST, Netherlands

In the nursing home they call me ‘boy with the curls’. My name is Teun Toebes, I’m twenty and very passionate about the need for human contact to improve the dignity of people with dementia. I won several awards and I was recently invited to meet the Prime Minister of The Netherlands. He told me that he was very impressed by the way I show people how to create little moments of happiness for people with dementia.

Just over one year ago I started making video’s to show people the diversity of the contact with people with dementia. For example, I went, together with 87-years young Lenie to Vlissingen beach. After paddling we visited a friend from her childhood who she had not seen for a long time. I saw Lenie hugging her friend after many years and this touching moment gave me goose bumps and a tear came to my eyes during filming. I saw a vulnerable woman change into a proud mother and friend.
At that moment I realised that the contact was what it was all about. It is all about the contact, the connection, the trust. That will be my message. All my colleagues in healthcare value the human touch and the human contact very much. The video reached over 1.5 million views on Facebook.

I would tell a story by images which touch the heart of the visitors. A message combined with the essence of healthcare, which in my opinion is, dignity.

We, as the environment of people with dementia, do have the responsibility to encourage them in life.

**PO4.15. Narrative inquiry on case studies of crisis in dementia**

**BOSCO Alessandro, SCHNEIDER Justine, COLESTON-SHIELDSDonna Maria, ORRELL Martin**

University of Nottingham, Nottingham, United Kingdom

**Purpose:** This study explored how people with dementia and their carers (i.e. the dyad) manage episodes of crisis.

**Design:** This was a case study approach. Participants were recruited from two teams managing crisis in dementia in the UK. We employed multiple qualitative interviews with people with dementia and their family carers over the course of one month. The analysis was first performed through thematic analysis. Inter-rater reliability was measured through Cohen’s kappa (K) and disagreements resolved through consensus. Data were further analysed through narrative inquiry to create a story line for our findings.

**Findings:** Five dyads were interviewed and a total of 16 interviews were conducted. Three dyads were husband-wife and two were daughter-mother relationships. The mean age was 67.4 for carers and 79.8 for people with dementia. Inter-rater reliability was ‘substantial’ (K = 0.73). In these cases, the carer assumed responsibility for managing the episode and was more likely to seek formal help if a pre-existing plan was in place. Otherwise, when a crisis arose, dyads preferred to avoid involving professionals.

**Originality:** The findings indicate that crisis teams are key for crisis support, and that early development of care plans is important to support the couple effectively.

**Practical implications:** Planning ahead for problems that may present is crucial from the earliest stage of diagnosis, and information around crisis teams should be provided at the time of diagnosis.

**PO4.16. Improving the involvement of people with dementia in developing technology–based interventions: a narrative synthesis review and best practice guidelines**

**RAI Harleen, CAVALCANTI BARROSO Aline, YATES Lauren, SCHNEIDER Justine, ORRELL Martin**

Institute of Mental Health, University of Nottingham, Nottingham, United Kingdom

**Background:** Technology can be helpful in supporting people with dementia in their daily lives. However, people with dementia are often not fully involved in the development process of new technology. This lack of involvement of people with dementia in developing technology–based interventions can lead to the implementation of faulty and less suitable technology.

**Objective:** This systematic review aims to evaluate current approaches, and create best practice guidelines for involving people with dementia in developing technology–based interventions.

**Methods:** A systematic search was undertaken in January 2019 in the following databases: EMBASE, PsycINFO, MEDLINE, CINAHL and Web of Science. The search strategy included search terms in three categories: “dementia”, “technology”, and “involvement in development”. Narrative synthesis wove the evidence together in a structured approach.

**Results:** Twenty-one studies met the inclusion criteria. Most studies involved people with dementia in a single phase such as development (n = 10), feasibility and piloting (n = 7), or evaluation (n = 1). Only 3 studies described involvement in multiple phases. Frequent methods for involvement included focus groups, interviews, observations, and user tests.

**Conclusions:** Most studies concluded it was both necessary and feasible to involve people with dementia, which can be optimised by having the right prerequisites in place, ensuring technology meets standards of reliability and stability, and by providing a positive research experience for participants. Best practice guidelines for the involvement of people with dementia in developing technology–based interventions are described.
multidisciplinary study, mental wellbeing of people living with early onset dementia is explored from the perspectives of social psychology and jurisprudence by focusing on their possibilities for agency, autonomy, and participation. The data consist of three focus group discussions with 12 participants, 8 women and 4 men, who have first-hand knowledge of the topic. In this presentation, we will discuss the prerequisites for mental wellbeing among people living with early onset dementia in the light of our results which illuminate the participants’ experiences of developing dementia while still employed, different kinds of resources that have helped them to cope with and manage changes in their lives, and the harmful impact of stigma. The results highlight the importance of workplace education, high-quality guidance and counselling as well as replacing harmful conceptions of and responses to dementia. This study is a part of an international multidisciplinary research project where we are scrutinising what happens when people develop dementia while still working (‘Dementia or mild cognitive impairment: @ Work in Progress’) and the Finnish project ‘Working Life and Memory Impairment – Mental Wellbeing, Legal Security and Occupational Capacity of People with Early Onset Dementia’ (WoLMI).

PO4.18. Staying Safe 'Going Out'- The experience of people affected by dementia

GAMBIER-ROSS Katie1, CLARKE Charlotte2, WILKINSON Heather3, WOOLNOUGH Penny4

1University of Edinburgh, Edinburgh, United Kingdom, 2Durham University, Durham, United Kingdom, 3Abertay University, Dundee, United Kingdom

Going outdoors is an important part of living well with dementia but people with dementia are at a high risk of going missing. High complex cases have a high mortality rate, place a high burden on police and result in immense stress for all involved. Often the concern about going missing leads to taking preventative measures, which can negatively affect quality of life. Little is known about how people with dementia navigate their environment or how they relocate themselves while lost. This research aims to explore the experience of ‘going out’ for people with dementia and their families and to explore how it affects their sense of purpose, agency and independence. Inclusive research methods such as facilitated discussion groups and walking interviews with people with dementia and their carers investigate how they engage with ‘going out’ and prevent being missing. Findings of this research will inform police search strategies when people with dementia are reported missing. An insight into the experience of people with dementia and particular coping strategies used will enable police to better ‘put themselves in the shoes of the person’ when conducting a missing person search. A wider aim of this research is to support people with dementia to live safely and independently in their communities.

PO4.19. The importance of international collaborations to address wayfinding and missing persons incidents

GAMBIER-ROSS Katie1, NEUBAUER Noelannah2, CLARKE Charlotte3, LIU Lili4, DAUM Christine5

1Ms, Edinburgh, United Kingdom, 2University of Alberta, Alberta, Canada, 3Durham University, Durham, United Kingdom, 4University of Waterloo, Waterloo, Canada

Going outdoors is an important part of living regardless of dementia diagnosis however, people with dementia are at a higher risk of getting lost, being unable to relocate oneselfs and being reported missing. Lost persons with dementia may lose the cognitive capacity to remember to drink water, eat, or protect themselves from extreme weather. If not found within 24 hours, up to half of these individuals experience death or serious injury. Research that focuses on managing, preventing, and understanding the behaviours associated with lost or missing persons who have dementia is limited and few involve key stakeholders, such as police, persons with dementia, and carers. These gaps have lead to the formation of an International Consortium on Dementia and Wayfinding. This consortium aims to address intersectoral and multi-disciplinary research and education, in partnership with stakeholders such as people living with dementia to affect policy. Since the consortium’s inception, the Consortium has: (1) held an inaugural meetings in Canada and Scotland, (2) completed a systematic review on the measured outcomes of wandering between universities in Canada and Australia, (3) mentored of undergraduate and graduate students in Canada and the Netherlands, and (4) began a study that evaluates the global perspective of dementia-related wandering among stakeholders. Future initiatives of the consortium include the development of a white paper on the current state of this field, and best practices for effective public awareness and knowledge mobilization on “wandering” and missing persons research.

PO4.20. Perspective on caring for someone living with dementia: A mixed-methods study on caregiver strain, quality of life and perceived health

DI LORITO Claudio1, BOSCO Alessandro1, GODFREY Maureen2, DUNLOP Marianne2, LOCK Juliette1, POLLOCK Kristian1, HARWOOD Rowan1, VAN DER WARDT Veronika3

1University of Nottingham, Nottingham, United Kingdom, 2PPI member, Nottingham, United Kingdom, 3Philips-Universität Marburg, Marburg, Germany

Background. Caring for someone with dementia is associated with negative and positive experiences. There is paucity of comprehensive evidence based on mixed-methods studies.

Objective. To present data around the experience of caring for someone with dementia, to identify needs and inform future service provision.
PO4.21. Value driven participation in co-creation of the virtual coach CAPTAIN to support independent living at home

ALMEIDA Rosa¹, LOSADA Raquel¹, BUENO AGUADO Yolanda¹, CID-BARTOLOMÉ Teresa¹, PETSANI Despoina², KONSTANTINIDIS Eudokimos², HOPPER Louise³, DIAZ-ORUETA Unai⁴, GABRIELLA IANES Patrizia⁵, KOUYOUMDJIAN Maria⁶, BAMIDIS Panagiotis⁷

¹INTRAS Foundation, Valladolid, Spain, ²AUTH - Aristotle University Thessaloniki, Thessaloniki, Greece, ³Dublin City University, Dublin, Ireland, ⁴Maynooth University, Maynooth, Ireland, ⁵Province of Trento Healthcare Agency (APSS), Trento, Italy, ⁶AMEN - Archangeliós Michael elderly people nursing home / rehabilitation centre for patients with alzheimer, Nicosia, Cyprus, ⁷AUTH - CAPTAIN Project Coordinator, Thesaloniki, Greece

Background: Population aging pose opportunities for service design centred in new interaction paradigms requiring adoption of more comprehensive design approaches. The European Project CAPTAIN (Coach Assistant via Projected and Tangible Interface, H2020_GA-769830) implements a hybrid participatory methodology for co-design and co-production of a home virtual eCoaching assistant, focusing on value co-creation and user experience.

Methods: CAPTAIN combines design thinking, participatory research, agile development and co-creation cycles. Five local stakeholder’s groups (GR,IE,ES,IT,CY) were constituted involving older adults (n=80), caregivers(n=22) and healthcare professionals (n=30). The initial workshop explored motivations driving participation and defined the user engagement methodology for the CAPTAIN Stakeholder Community. Insights oriented the planning of co-creation activities considering participant’s diversity, a focus on inclusive and accessible participation, and creation of a respectful, joyful and safe environment. Two workshops explored user and system requirements through use-case driven insights on how technology could support identified needs; two co-production cycles followed, with experimentation of a “minimum viable product”.

Results: Willingness to participate was intrinsic (esteem-building, self-actualization, self-improvement), extrinsic (relatedness) and altruistic, by the desire to contribute to the common good. The use of tangible products presenting easy to follow interactions, co-creative and cognitively accessible tools facilitated the engagement of older adults with mild cognitive decline as co-designers and co-researchers. Participants provided insights on expected value (support autonomy, dignity, independence) and ethical concerns (secure, accessible, unobtrusive, dignifying, decision-making respectful/supporting user to hold locus of control), orienting improvements in designs, interaction and content, in a very early development phase. Conclusion: Although the potential to maximize the value delivered and the requirements traceability was met, divergent views collected challenged the researcher team when prioritizing CAPTAIN components and features. Conflicts were usually resolved by focusing on the highest end-user value. Co-creation learning journey results enable the transfer of the hybrid co-creation value-driven approach to new research fields.

PO4.22. Intercultural care for people with a migration background with dementia

MONSEES Jessica, SCHMACHTENBERG Tim, THYRIAN Jochen René

German Center for Neurodegenerative Diseases, Greifswald, Germany

Background: Due to increasing numbers of older people with a migration background (PwM), it can be assumed that the number of older PwM with dementia might increase as well (Schouler-Ocak et al., 2015). For the year 2018, the number of PwM with dementia in Germany was estimated at around 96,500 (Monsees et al., 2019). PwM with dementia and their family caregivers face various challenges in the provision of care, such as language barriers, a lack of culturally sensitive information and services (Bermejo et al., 2012). In view of these challenges and the presumably increasing number of people affected, interculturally sensitive care is all the more important. In order to provide such care, health systems and providers of care services should respond appropriately to this particularly vulnerable population to provide them with the help and support they need.
Research question: What are important factors of intercultural care for PwM with dementia or more specifically which requirements and aspects are necessary to ensure an intercultural care for PwM with dementia?

Method: In order to answer the question, a systematic literature search in the databases PubMed, PsycInfo and Psychology and Behavioral Sciences Collection is conducted.

Expected results: Results on factors such as intercultural competence and care models, ethical aspects, cultural knowledge and awareness, aspects of communication and interaction, among others will be discussed. These will provide information about which components should not be missing in interculturally sensitive care and which aspects should be given special attention.

Discussion: The results of this study can provide guidance for both decision-makers in the healthcare system and providers of care services to help them develop and implement strategies for culturally sensitive care for PwM with dementia.

**PO4.23. Shaking professionals’ caregiving foundations: experiences with problem behaviour in people with dementia from minority ethnic groups**

CORINA Bosma¹, SMITS Carolien²

¹Carintreggeland, Hengelo, Netherlands, ²Pharos, Dutch Center of Expertise on Health Disparities, Utrecht, Netherlands

Aim: In residential and home care, professionals are caring for a growing number of people with dementia from minority ethnic groups. Carers aim to provide person centered care, also in case of behavioural problems or poorly understood behaviour. This qualitative study aims to gain insight in professional carers’ experiences with problem behaviour in migrants with dementia.

Method: Semi-structured interviews with twenty professional carers in home and residential care in an organization for health and social care in the east of the Netherlands. Interview transcripts were analysed using open coding.

Results: Three themes emerged from the data: Problem behaviour, Working on Good Care, Dynamic care values.

Problem behaviour is reported to be similar in older migrants and in autochthonous clients, when carers associate it with dementia itself. Miscommunication due to language limitations and cultural differences are seen as typical for problem behaviour in migrants. Caregivers may make successful efforts to deal with problem behaviour in a person centered way, e.g. by learning some words in the client’s native language or by playing matching music. Unsuccessful attempts, however, result in frustrations in both clients, carers and relatives. Some relatives are perceived to be causing problem behaviour, e.g. when they disrupt the quiet ward atmosphere by visiting in great numbers. Furthermore, relatives may not understand the nature of dementia or respect the carers’ work. Frustrations make carers reflect on what constitutes person centered care for migrants. Care organisations may help by offering carers intercultural insights and support.

Conclusion: Despite carers’ many efforts to provide good personal care, problem behaviour in people with dementia from minority ethnic groups may lead to frustrations in both clients, relatives and professional carers. Failure to ease the behaviour shakes the professionals’ person centered care foundation. Professionals need support at the individual, team and organizational level.


UTOMO Amalia Fonk

Stichting Alzheimer Indonesia Nederland, Groningen, Netherlands

Background: Alzheimer Indonesia and Alzheimer Netherlands have a strong collaboration under the Twinning Program of Alzheimer’s Disease International. This is a three-year collaboration for 2017-2019 and actually a renewal of a previous program.

Objective: To exchange information, support and learn from each other and for Alzheimer Indonesia to benefit from the organizational experience from Alzheimer Netherlands to improve quality life of people with dementia and caregivers.

Activities: Adapting Alzheimer Nederland’s handbook “Dementie en Nu?”(Dementia and next?) to Indonesian Language and Culture. The project is involving crowd collaboration within the volunteers in Indonesia and The Netherlands, inter-generations (14 – 68 years old) and multi discipline. From translators, editors, photographers, illustrators and designer.

Supported by Indonesian Embassy in The Netherlands.

Result: The book is being printed more than 5000 pieces supported by Alzheimer Nederland, Online Crowd Funding kitabisa.com and Werkgroep 72Dutch Charity Organisation. Distributed to 22 Alzheimer Indonesia’s chapter across Indonesia and overseas. Soft copy can be download in Alzi Ned’s and Indonesia Embassy in Den Haag website.

Alzheimer Nederland received a three-year grant from the Ministry of Health to support the program financially in collaboration with Alzheimer Indonesia and Alzheimer Indonesia Nederland. And we hope to extend the Twinning Program for the next couple of years.
PO5. Policy

PO5.1. Understanding of dementia in Poland - lexical semantic analysis of otępienie (English 'dementia') in Polish language

MACZKOWIAK Maria1, LIBURA Agnieszka2, SCZESNIAK Dorota1, CIUKOWICZ Marta1, DUDA-SIKULAK Marta1, RYMASZEWSKA Joanna1

1Dept. of Psychiatry, Wrocław Medical University, Wrocław, Poland, 2Institute of Polish Philology, University of Wrocław, Wrocław, Poland

Introduction: Language is an impactful transmitter of socially shared beliefs and perceptions and can perpetuate patterns of thinking and behaving among people. This power of language has been frequently signalized by dementia activists who perceive the dementia discourse as highly stigmatizing. Basic issue is the term dementia itself and its understanding among users of a given language.

In Polish dementia is otępienie which could be translated as torpor, numbness, stupidity, etc. These common meanings give rudiments for inferring the role which semantics might play in the process of stigmatization of the condition among Polish speakers. Cognitive analyses of understanding otępienie by Polish speakers who are involved in creating dementia discourse may provide a background for anti-stigma initiatives.

Aim: Reconstruction and comparisons of the cognitive frames of otępienie in Polish from the three-fold perspective of care partners of people living with dementia, health care providers and lay-public.

Method: Based on the theory of the Frame Semantics of Charles Fillmore reconstruction of the cognitive frames of otępienie in Polish language was performed. Qualitative and quantitative methods were applied to analyse the data form National Corpus of Poland and linguistic surveys which were conducted among care partners of people living with dementia, health care providers and lay-public.

Results & conclusions: Cognitive frames of otępienie reconstructed within the current study provide an insight into understanding of dementia among Polish speakers with a distinction into three social groups with different experiences with the condition. The results form the basis for medical communication, e.g. for addressing tailored social messages within behaviour change campaigns. Moreover, they create a foundation for further research on determining the relationship between semantics of dementia and the stigma present in a given society.

PO5.2. Withdrawn

PO5.3. Improving the quality of life of people with dementia living in nursing homes: the accreditation process of care home providers in Forli

BOSCHI Federica1, MARIANI Elena1, NUGHINI Silvia1, ZACCHERONI Cristina2, BONI Stefano3, BENATI Giuseppe1

1Memory Clinic, Morgagni-Pierantoni Hospital, AUSL Romagna, Forli, Italy, 2Comune di Forli, Forli, Italy, 3Distretto di Forli, AUSL Romagna, Forli, Italy

Background: Emilia-Romagna Region is involved in the accreditation process of healthcare structures and in the identification of the necessary requirements to evaluate and accredit facilities that offer healthcare services to population (Regional Resolution no. 514/2009). One of these requirements concerns the development of a dementia-care programme to improve the quality of life of people with dementia living in nursing homes.

Methods: In order to identify the most important dementia-care issues to be discussed and improved, a brainstorming session among the representatives from the main elderly care services of Forli and its surroundings was conducted. Specifically, representatives of the memory clinic, the nursing and social care areas of the Forli Hospital as well as of eight nursing home care providers and of the Municipality were involved. Four topics arose and participants were consequently divided into four groups: environment, personalized and continuation of care, palliative care, professionals' training. Within each group, participants were asked to discuss how to improve the issue identified, considering the care procedures already in place and the available documentation.

Results: Each group developed specific strategies to be implemented within the involved nursing homes. The ‘environment’ group developed a list of practical indications on how to make the environment more suitable for residents with dementia. The ‘personalized and continuation of care’ group developed guidelines to improve the communication of information between the NHS services and nursing homes as well as a chart to be used when the resident is in need to be referred to an NHS specialist. The ‘palliative care’ group described recommendations on end-of-life care in dementia. The ‘training’ group organized two specific trainings in dementia care for professionals.

Discussion: The results were presented in two public conferences. Another meeting will be organized to analyse the implementation process of the identified strategies in the involved nursing homes.

PO5.4. Withdrawn

PO5.5. Involving indonesian students and association in the Netherlands

UTOMO Amalia Fonk
Background: In 2019, according to Nuffic Neso Indonesia, there were 2,500 Indonesian students in the Netherlands who were following bachelor, master and PhD programs from various disciplines. These numbers have been increasing every year. Most students return back to Indonesia after finishing their study bringing an advanced knowledge and practice for their benefits. Young professionals can promote new perspective for social change and knowledge transfer. By having more experienced young resources, it is expected that awareness of dementia is increased as well among them to end the negative stigma in Indonesia.

Objective: To empower Indonesian students in The Netherlands and enable exchange knowledge to promote the public awareness of dementia.

Activities: Collaborations between the Foundation and Indonesian students occurred through the Indonesian Student Association activities, the Foundation events and programs, or through Individual involvement. Collaboration on a number of students' events to encourage youth awareness, risk reductions and team work

Student Association activities: Sport, Social. Culture and Religious events.

Foundation events: Social, Culture and Education.

Key Messages and Activities in each events covers: Education of 10 signs of dementia, Poco-Poco Risk Reduction Dance, Brain Gym and Fundraising.

Individual involvement: participation as a volunteer or internship, maintenance of social media, blog writing, participation in webinar sessions and fundraising.

Result:
- The activities of the Foundation and Dementia Awareness topics become more popular among the youth.
- Students develop an experience in teamwork through a recognizable foundation that adds value during their study period in The Netherlands.
- Students have the opportunity to get in contact with the Alzheimer Indonesia Chapter in their hometown in Indonesia for future collaboration.

PO5.6. First steps to Dementia Friendly Community in Formigine: measure of community attitude towards people living with dementia

ROVATTI Tonino², MANNI Barbara¹, FABBO Andrea¹, GARISELLI Daniela³, ZARZANA Paolo³, RONCHETTI Federica⁴

¹Modena Health Authority and Services, Modena, Italy, ²Alzheimer Association ASSsDe, Sassuolo, Italy, ³Municipality, Sassuolo, Italy, ⁴Sassuolo Health Authority and Service, Sassuolo, Italy

The number of people living with dementia (pwd) is increasing as a result of population aging. Cognitive impairment and neurological changes result in disability. World Health Organization promotes social inclusion’s initiatives for pwd. The World Alzheimer report 2019 urges community to fight against the stigma about this condition. Communities where pwd are able to remain socially included are known as dementia-friendly communities (DFC). In Italy Alzheimer Association encouraged 24 CFD, Formigine was the first DFC in Emilia Romagna Region. A promoting group involved Alzheimer Association (ASSsDe), Municipality and Health Service gathering them at the end of 2019. To understand the local impact of marginalisation and inequality on the community, a social survey in a Facebook page of Formigine explored attitude or stigma toward pwd. 62 questionnaires were collected. People expressed availability to help pwd and share community spaces with them but they complained lack of knowledge about disease, about what pwd are able to do and how to approach them. Exploratory questionnaire was given to 42 pwd and 14 caregivers to know their needs and point of view. Half of pwd showed lack of insight about cognitive deficits. They referred to be globally satisfied about their life even if they complained to be boring most of time, to feel teased or uncomfortable in community. Most of them have abandoned more than 3 activities or hobbies. On the other hand, Caregivers feel unable to satisfy pwd needs and most of them think that after diagnosis, community offers less opportunities to social engagement. Two focus groups were organized. In the first group with caregivers’ barriers and opportunities in the community were analyzed. In the second focus group, people living with mild-moderate dementia were involved to expose difficulties in daily living in the community. Municipality promoted DFC with an official resolution and a public open conference.

PO5.7. The responses of pasar indonesia raya visitors after experiencing dementia virtual reality in the Netherlands

GALUH Sekar¹, KHRISMA YEKTI Manik², SETIADI Tania¹

¹Stichting Alzheimer Indonesia Nederland, Groningen, Netherlands, ²Stichting Alzheimer Indonesia Nederland, Zoetermeer, Netherlands

Background: Stichting Alzheimer Indonesia Nederland (AlziNed) participated in the biggest annual event of Pasar Indonesia Raya (Pandora), which was organized by the Embassy of the Republic of Indonesia in Rijswijk, The Netherlands on September 13th - 15th, 2019 as a celebration of the 74th Indonesian Independence Day. To broadcast information about dementia among visitors across the Netherlands, AlziNed provided some information tools and activities, including brochures, flyers, and books. However, a new tool is needed to stimulate dementia experience, which may improve people’s awareness to reduce
the stigma of dementia. Virtual Reality (VR) ‘A Walk Through Dementia’ tool that is developed by Alzheimer’s Research UK was used as a new and unique instrument to deliver an insight into life with dementia in an interesting manner. It has successfully captivated visitors’ attention to visit, have experience with the VR, share their opinions, and subsequently receive information about dementia.

Objective: To evaluate Pandora visitors’ perspectives and awareness about people with dementia after experiencing VR instruments.

Method: A VR tool ‘A Walk Through Dementia’ that is developed by Alzheimer’s Research UK was used. Pandora visitors who had the opportunity to experience the activity of people with dementia through VR, were asked to write free-text comments.

Result: There were 22 free-text responses analyzed. All responses illustrated visitor’s feelings and emotions after experiencing VR. The opportunity to experience the activity as people with dementia increased the knowledge and awareness of the visitors towards dementia. Moreover, some comments also described a positive attitude to support people living with dementia.

Conclusion: A VR is an interesting instrument to promote emotions that may encourage public awareness of dementia.

PO5.8. The program, knowledge, awareness and attitude project: Stichting Alzheimer Indonesia Nederland’s evaluation

SETIADI Tania1, KHARISMAYEKTI Manik2, GALUH Sekar1
1Stichting Alzheimer Indonesia Nederland, Groningen, Netherlands, 2Stichting Alzheimer Indonesia Nederland, Zoetermeer, Netherlands

Background: Stichting Alzheimer Indonesia Nederland (AlziNed) is a foundation based in Groningen that aims to improve the quality of life of the elderly, people with dementia and caregivers amongst Indonesian or those with Indonesian background who reside in The Netherlands. As a part of the Alzheimer’s Disease International’s three-year Twinning Program (a collaboration between Alzheimer Indonesia and Alzheimer Netherlands) from 2017 to 2019, a number of activities have been organized by AlziNed across cities and communities in The Netherlands, such as awareness campaign, seminar, fund raising, and cultural activities. However, an evaluation is needed to figure out the best manner to achieve the goals of the organization and to improve future activities planning.

Objectives: The Program, Knowledge, Awareness and Attitude (PROKAA) project aims to evaluate and measure the impact of the Stichting Alzheimer Nederland programs between 2017-2019.

Method: A questionnaire was developed to collect the information from the respondents. The respondents were those who are listed at AlziNed database as volunteers, dementia friends, or participants in AlziNed activities. The questionnaire was delivered in two languages (i.e. Bahasa Indonesia and Dutch) to allow the respondents to choose the survey language. It comprised of close- and open-ended questions and was divided into three main sections:

- Demographic data (i.e. age, gender, education, place of origin in Indonesia, residency status) to describe the respondents’ characteristic.
- Programs. This section is intended to evaluate the tools and activities that have been conducted by AlziNed within the three-year period.
- Impact. The last section is intended to assess the knowledge, awareness and attitude of the respondents towards dementia after participating in AlziNed activities.

The questionnaire was planned to be distributed both online and offline. However, due to Covid-19 pandemic, the latter option has been postponed. The data collection and analysis are expected to be completed by summer 2020.

PO5.9. Withdrawn

PO5.10. Dementia action plan: focusing on prevention and families

EGERVERARI Agnes
Social Cluster Association, Budapest, Hungary

Dementia Action Plan is a national level program that has been developed last year in Hungary. Its key words are: prevention, relationships and communication - not only inside the care system, but also with other different professionals, with the whole society.

Background: Every second citizen in Hungary has insufficient health literacy. Those people do not know how to keep our health, where to turn to if having any health problem. This is especially true in case of dementia, as the taboo here makes the situation even more challenging.

INDA© program developed by the Social Cluster Association improved relationships and communication between different professionals, families, and policymakers.

Method: The interprofessional approach is the guiding principle of the Action Plan for more effective cooperation between Long-Term Care (LTC) facilities and health care system.
Prevention: Three Generations for Health Program: also contributes to the changing general practitioners’ attitudes towards person based dementia care. The main result of the program is the diagnostic of thousands of people over 65 years old.

Knowledge about dementia should also be a component part of continued further education in the medical profession.

To concentrate on support of families; the maintains the best QoL. Training for informal careers aims to share practical knowledge about changing roles in the family; legal questions, etc.

Awareness raising campaigns and support groups for caring families the dementia advisor is a new professional who connects a PwD, a caring family and the health/social care system. Having relevant knowledge about dementia, he/she is also able to navigate in the care system. This concept’s goal is to optimize the level and timing of the support.

The attitude towards dementia is changed in Hungary – Dementia Action Plan serve a useful framework to improve the quality of life for people living with dementia.

**PO5.11. Digital services for dementia from the perspective of service providers: digiDEM Bayern**

REICHOLD Michael¹, DIETZEL Nikolas², KOLOMINSKY-RABAS Peter L.², GRAESSEL Elmar³, PROKOSCH Hans-Ulrich¹

¹Medical Informatics, Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium 'Digital Dementia Registry Bavaria – digiDEM Bayern', Erlangen, Germany
²Interdisciplinary Center for Health Technology Assessment (HTA) and Public Health (IZPH), Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium 'Digital Dementia Registry Bavaria – digiDEM Bayern', Erlangen, Germany
³Center for Health Services Research in Medicine, Department of Psychiatry and Psychotherapy, University Hospital Erlangen, Friedrich-Alexander University Erlangen-Nürnberg (FAU); Project consortium 'Digital Dementia Registry Bavaria – digiDEM Bayern', Erlangen, Germany

Background: The increasing number of people with dementia and their caregivers will require a change in the provision of dementia-related services in the future. Digital technologies offer new ways of addressing this situation and provide a possible solution.

Research question: How do service providers assess the current landscape with classic (non-digital) and digital dementia-related services?

Method: The project "Digital Dementia Registry Bayern" (digiDEM Bayern) was launched in 2019 to improve the situation of people with dementia and their caregivers in Bavaria (one of the federal states of Germany) effectively and sustainably. As part of the project, an online survey was conducted among providers of dementia-related services in Bavaria over a two-month period (mid-May to mid-July 2019).

Results: The results of the survey have shown that the provision of non-digital services is currently consistently rated better than that of digital services. In the field of digital services, the category 'information' scored best (rated good/very good by 48.5%). The categories 'exchange' (18.6%) and 'training' (17.5%) follow by far. The categories 'Consultation' (10.3%) and 'Intervention' (9.2%) received the lowest scores.

Conclusion: There is great potential for improvement in almost all categories of digital offerings. In these times of increasing IT affinity among the target group, it is important to further expand the digital forms of offerings and thus overcome supply barriers and gaps. The digiDEM Bayern project with its digital service offers based on a digital platform and its digital registry will help to improve the situation of people with dementia and their caring relatives, especially in rural areas.

Funding: digiDEM Bayern is funded by the Bavarian Ministry of Health and Care as part of BAYERN DIGITAL II (funding code: G42d-G8300-2017/1606-83).

**PO5.12. Withdrawn**
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