JULY-AUGUST 2023

ALZHEIMER EUROPE NEWSLETTER

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HIGHLIGHTS IN THIS ISSUE

WELCOME

I trust you have all had a good summer. As every year, this edition covers news from both July and August.

I would like to start by congratulating colleagues in Slovenia, where the Government has approved a new national dementia strategy. Our member association, Spominčica was the initiator of the country's first national dementia strategy and has been a very active member of the working group for the preparation of this second strategy.

I would also like to congratulate the organisers of the Alzheimer's Association International Conference (AAIC), which took place in Amsterdam in July. Several members of the Alzheimer Europe (AE) team, myself included, travelled to the event, which brought together a huge number of participants, in an atmosphere of optimism and excitement. We were delighted to be there and to hear, first-hand, updates from researchers, organisations and companies, including the results from Lilly's clinical trial of donanemab. This, and other AAIC highlights, can be found in our "AAIC Watch" news section, on pages 14- 17.

In other important research news, the US Food and Drug Administration (FDA) has granted traditional approval to lecanemab, marketed by Eisai and Biogen for the treatment of early Alzheimer's disease (AD). We welcome this traditional approval by the FDA, and the expansion of access to disease-modifying treatments for early AD in the US. This gives hope to many who have long been awaiting therapies to slow or delay the cognitive and functional decline caused by AD. While Europeans cannot yet access the treatment, as it is currently undergoing a full evaluation by the European Medicines Agency, we hope for a similarly positive outcome. The decision is expected by the end of 2023.

Our work with EU-funded projects has continued throughout the summer months and, aside from the many project meetings attended, two project papers co-authored by members of the AE team have been published: One on the ethical challenges of using remote monitoring technologies for clinical research, by the RADAR-AD project; and one on precision medicine in neurodegeneration, published by IHI-PROMINENT.

Our own meetings and events have not taken much of a break, either, with another popular session of our online Alzheimer's Association Academy series being held, this time focusing on young onset dementia, and with October fast approaching, there have been many conference-related meetings taking place also. We are delighted to announce that ten early-stage researchers have won bursaries provided by the Alzheimer Europe Foundation to attend and present their innovative research at the upcoming conference and we look forward to welcoming them, and you, to Helsinki!

In closing, I would like to draw your attention to two new open positions in our team. Both are full-time permanent positions - a Public Involvement Officer and a Project Officer. If you, or anyone you know, are interested, please apply before 30 September!

Jean Georges
Executive Director

Sponsor of the month

Alzheimer Europe would like to express its gratitude to its first sponsor for 2024!

Read more about sponsorship opportunities here: https://www.alzheimer-europe.org/about-us/governance/finances/2023-sponsorship-opportunities

DANONE

ALZHEIMER EUROPE

4 July: Our summer Alzheimer's Association Academy focuses on young onset dementia, sharing learnings, lived experiences and good practice

On 4 July, we hosted the latest edition of our Alzheimer's Association Academy. The Academy meetings are capacity-building workshops for our member organisations, people with dementia and carers, together with researchers, policymakers, industry representatives and other stakeholders. The focus of the Academy meeting was on providing services and support for people with young onset dementia, which affects almost 4 million people worldwide.

The term "young onset dementia" (YOD) is used to describe any form of dementia that develops in people under the age of 65. Although YOD is rarer than later onset forms of dementia, there are still 370,000 new YOD cases annually worldwide. And while YOD is similar to other types of dementia in some ways - causing symptoms such as memory loss, changes in mood and personality - the disease can have a different impact as younger individuals are more likely to be employed full time, raising a family or financially responsible for a family. Also, since health care providers generally don't look for dementia in younger people, getting an accurate diagnosis can be a long and frustrating process. Similarly, services and support may be hard to access, and may not be tailored to the particular needs and preferences of people with YOD.

The first Academy speaker was Pia Knudsen, who shared her perspectives on living with young onset dementia. Pia, a member of the European Working Group of People with Dementia (EWGPWD), lives in Denmark and was diagnosed with dementia in her mid-50's. Pia explained that she is a visual artist, designer and teacher, and spoke vividly about how she felt when she was diagnosed, how her life has changed since her diagnosis, and the way she draws inspiration and new perspectives from her children, students and friends. Through examples of her art, Pia eloquently illustrated the impact of a YOD diagnosis. Next, Christian Bakker (Radboud University Medical Center, the Netherlands) spoke about the global prevalence of YOD, as well as timely diagnosis and support needs in YOD. Christian explained that people with YOD can wait up to 5 years for diagnosis, which makes it much harder for them and their families to access support and psychosocial interventions, which could help build capacity, allowing people to live well with YOD, for longer.

Following on in the same theme, Jan Oyebode of the University of Bradford (UK) spoke about the Angela project, which aims to improve diagnosis and post-diagnostic support for YOD. The project included a range of different studies, Jan explained, from interviews with service providers for people with YOD, to Delphi studies, national surveys, and focus groups. The results highlighted a major lack of service support for people with YOD: almost 40% of people with a YOD diagnosis had not seen a health professional in the last 3 months, and 57% of family members said they provided over 5h of care a day, with little respite support. An important observation was that specialist services for YOD were much better equipped to provide quality care than "all age" services, maintaining activity and engagement with their patients. The last speaker of the Academy meeting was Susanna Saxl-Reisen of the German Alzheimer's Association (Deutsche Alzheimer Gesellschaft). Susanna spoke about support provided by national patient associations to people with YOD, who number over 100,000 in Germany. She highlighted a broad range of activities targeted at people with YOD, such as support and activity groups, helplines and psychoeducational training and guidance. Supporting families and caregivers is also crucial, Susanna emphasised, explaining how projects such as KIDSDEM and RHAPSODY have created educational materials, care structures and capacity-building workshops. The Academy meeting finished with an interactive roundtable and lively discussions on challenges and enablers for improved services and support for people with YOD.

11 July: Alzheimer Europe collaborates with project DECIDE-SR to help create a framework for the active involvement of people living with dementia in systematic reviews

Systematic reviews summarise and evaluate studies on a particular topic. They provide information, for example, regarding whether an intervention is beneficial. This type of review is particularly important for healthcare professionals because they can use the results of the review to guide their actions. There is a growing awareness that the public, including people living with dementia and their close contacts (both family and non-family), need to be actively involved in the process of preparing these reviews when they are concerned with the topic of said reviews. Despite this consensus, it is often the case that only healthcare professionals are involved, without the "experts by experience" themselves.

At present, there is a lack of a dementia-sensitive framework to actively involve people living with dementia and their close contacts, together with healthcare professionals, as co-researchers in systematic reviews. The Deutsches Zentrum für Neurodegenerative Erkrankungen (DZNE) decided it was important to develop such a framework in order to inform practice and, with this in mind, it launched a project called DECIDE-SR. The framework that is being developed by the project will later be made available to the public free of charge to increase awareness of this topic and to contribute towards more frequent, well-organised and meaningful involvement of people living with dementia and those close to them, in systematic reviews.

On 11 July 2023, the researchers published a paper in the BioMed Central (BMC) journal of Research Involvement and Engagement, entitled "Participatory development of a framework to actively involve people living with dementia and those from their social network, and healthcare professionals in conducting a systematic review: the DECIDE-SR protocol". Alzheimer Europe is collaborating with DECIDE-SR and our Director for Projects Dianne Gove and Project Officer Ana Diaz are both co-authors. Dianne and Ana work closely with the European Working Group of People with Dementia (EWGPWD) and we are delighted to see that the group's former (and founding) Chairperson Helga Rohra is involved in the DECIDE-SR project and is also a co-author of this new paper. Read the full paper, here:

https://researchinvolvement.biomedcentral.com/articles/10.1186/s40900-023-00461-2

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16-20 July: Alzheimer Europe actively participates in Alzheimer's Association International Conference (AAIC) in Amsterdam

Alzheimer Europe was well-represented at this year's Alzheimer's Association International Conference (AAIC), which took place in Amsterdam from 16 to 20 July. Executive Director Jean Georges was in attendance, as were Project Officers Ana Diaz, Angela Bradshaw and Cindy Birck.

Prior to the start of AAIC, Jean Georges attended a round table on Alzheimer's disease supported by Novo Nordisk on 15 July. He also represented the EU-FINGERS project at a meeting of the Worldwide FINGERS (WW-FINGERS) Network hosted by the Alzheimer's Association where updates were provided on multi-domain interventions in Canada, Finland, Ireland, Japan, Latin America, the Netherlands, South Korea, Sweden, the United Kingdom and the US. He also attended a meeting of the International Scientific Advisory Board of the Alzheimer Centre Amsterdam on 19 July and was able to have bilateral meetings with a number of Alzheimer Europe partners and sponsors: Alector, Alzheimer's Association (US), Alzheon, Biogen, BMS, CEOi, Eisai, GSK, Icometrix, Lilly, Merck, Novo Nordisk, PPD, TauRx and the World Dementia Council.

On 17 July, at a featured research session entitled "Patient and public involvement in dementia research: Global perspectives", chaired by Helen Bundy Medsger and Sarah Walter, Ana Diaz gave a presentation on "Involving people with dementia in dementia research: principles, challenges and practical examples", together with Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD). They discussed the public involvement (PI) work conducted by Alzheimer Europe and outlined the activities of the EWGPWD, the achievements, as well as sharing some of the challenges encountered along the way.

At the same session, Cindy Birck discussed public involvement in the JPND-funded EU-FINGERS project, alongside project partners and Nick Montague, a member of the EU-FINGERS Advisory Board hailing from Luxembourg. They presented the PI work conducted within the EU-FINGERS project and the

Advisory Board which is led by Alzheimer Europe and coordinated with project partners. They covered aspects of the Advisory Board's organisation and strengths as well as some of the more difficult aspects of the work encountered during the project.

Angela Bradshaw represented the European Platform for Neurodegenerative Diseases (EPND) project at the event, where she was also a featured guest at the Alzheimer's Disease Data Initiative (ADDI) stand. The overarching goals of ADDI's AD Workbench are to encourage researchers to share datasets and resources in a secure, transparent way, and also to foster the development of new, shared tools and analytics for the benefit of the whole AD research community. The Workbench powers the EPND project's platform. Both at the EPND stand and at the ADDI stand, Angela shared information about the new EPND Cohort Catalogue and about data and bio samples available for access.

In the EU Projects news section of this newsletter, on pages 6-10**,** we have summarised the involvement of the EU-FINGERS and EPND projects at AAIC, and have also reported on the WW-FINGERS Network Meeting. The LETHE project also presented a poster as part of the conference programme and Ana Diaz was a co-author of this poster presentation. LETHE is a personalised prediction and intervention model for early detection and reduction of risk factors causing dementia, based on Artificial Intelligence (AI) and distributed Machine Learning.

A number of important research updates were presented during AAIC 2023. We have selected some of the highlights to share in our summer 2023 newsletter. You can find these in our special "AAIC Watch" news section, on pages 14-17.

26 July: Congratulations to then ten early stage researchers who won Alzheimer Europe Foundation bursaries to attend and present at the 33rd Alzheimer Europe Conference!

We are delighted to announce the early stage researchers who have been selected by our jury, to benefit from the bursaries provided by the Alzheimer Europe Foundation to attend and present at the 33rd Alzheimer Europe Conference, in Helsinki in October.

The selection of the ten bursaries was based on the best average scores each received from the jury members. Each of them was informed about the exciting news on 26 July 2023.

Here are the details for the special session we have organised to showcase their work, "SS2. Dementia Researchers of the future", taking place on 17 October from 12:00 - 13:00:

12:05 - 12:10 (SS2-01) Drivers with cognitive impairment or dementia: the development of a new center for driving assessment and support in Portugal
Natália Duarte, Portugal

12:10 - 12:15 (SS2-02) COVID-19 and cognitive impairment in older adults: Longitudinal analysis from the PREDIMED-PLUS Cohort
Carlos Gómez Martínez, Spain

12:15 - 12:20 (SS2-03) Photovoice practice and carer of people living with dementia involvement for transformative change in Lithuania
Ieva Petkutė, Lithuania

12:20 - 12:25 (SS2-04) Engaging participants in lifestyle interventions to prevent cognitive decline: The role of psychoeducation in the PENSA study
Thais Lorenzo, Spain

12:25 - 12:30 (SS2-05) Acceptability of the Social Robot Mini and Attitudes of People with Dementia and Mild Cognitive Impairment
Aysan Mahmoudi Asl, Spain

12:30 - 12:35 (SS2-06) Down Syndrome - Basque Alzheimer Initiative (DS-BAI): Integrative health care plan based on personalized medicine and clinical-biological research cohort
Miren Altuna Azkargorta, Spain

12:35 - 12:40 (SS2-07) Music-making for older people with and without dementia in residential care facilities: Preliminary findings from a community music intervention
Rafaela Troulou, Greece

12:40 - 12:45 (SS2-08) Including the socio-emotional approach in a finger-like multi-domain intervention to prevent cognitive decline. CITA Go-On Study
Naia Ros, Spain

12:45 - 12:50 (SS2-09) Premorbid personality traits and their relationship with functional impairment in early-stage behavioural variant frontotemporal dementia
Electra Chatzidimitriou, Greece

12:50 - 12:55 (SS2-10) Attitudes, motivations, and barriers to pre-symptomatic Alzheimer's disease screening: a comparison between informal caregivers in five European countries
Marina Makri, Greece

This session is supported by the Alzheimer Europe Foundation, the INTERDEM Academy and Roche and will be dedicated to 10 early stage researchers giving five minute presentations on innovative approaches to dementia.

If you have not yet registered for our Annual Conference, you can do so via this link:

https://www.alzheimer-europe.org/conferences/2023-helsinki/online-conference-registration

31 July: WHO Global Dementia Observatory Knowledge Exchange Platform includes Alzheimer Europe and NHS England joint guide on intercultural dementia care

People from ethnic minority communities often face delays in dementia diagnosis, barriers to services and there is insufficient culturally competent dementia care available. Earlier this year (15 May 2023), NHS England (NHSE), working in partnership with Alzheimer Europe, published a guide on intercultural dementia care, for health and care professionals, aiming to improve care for people living with dementia from an ethnic minority background. During July, this important resource was accepted by the World Health Organization (WHO), for inclusion on the WHO Global Dementia Observatory Knowledge Exchange (GDO KE) Platform. The process for inclusion of this resource included a review by the WHO secretariat together with the GDO KE peer review panel and Focus Group of people with lived experience.

Alzheimer Europe is delighted to have its yearbook shared via this important platform. It can be accessed here:

https://globaldementia.org/en/resource/intercultural-dementia-care-a-guide-for-health-and-care-workers

GDO KE Platform homepage: https://globaldementia.org/en

ALZHEIMER EUROPE NETWORKING

On 3 July, Dianne and Ana met with members of the EWGPWD for the preparation of the group's plenary session at the AE conference.

On 3 July, Angela met with Regenlife.

On 3 July, Jean met with Essity.

On 4 July, Alzheimer Europe organised an Alzheimer's Association Academy on "Providing services and support for people with young onset dementia".

On 5 July, Owen attended a European Commission/World Health Organization briefing on the partnership for long-term care.

On 6 July, Ana, Soraya and Chris attended the general Assembly meeting of the ADIS project.

On 6 July, Jean attended a meeting of the GSK Health Advisory Board.

On 7 July, Dianne and Ana met with the Chairs of the AAIC Public Involvement session to discuss their presentations at the AAIC conference.

On 10 July, the Alzheimer Europe Anti-Stigma Award Committee met.

On 14 July, Angela met with communications representatives at EBRAINS.

On 16 July (Amsterdam, Netherlands), Jean attended the meeting of the WW Fingers collaboration.

From 16 to 20 July (Amsterdam, Netherlands), Jean, Ana, Ange and Cindy attended the Alzheimer's Association International Conference (AAIC)

From 16 to 20 July (Amsterdam, Netherlands), Jean met with representatives of Alector, Alzheimer's Association, Alzheon, Biogen, Bristol Myers Squibb, Davos Alzheimer's Collaborative, Eisai, Icometrix, Fundació Pasqual Maragall, GSK, Lilly, MSD, Novo Nordisk, PPD, Prothena, Scottish Brain Sciences, TauRx and the World Dementia Council.

On 17 July (Amsterdam, Netherlands), Ana and Ange attended a meeting of the EPND consortium.

On 17-18 July (Amsterdam, Netherlands), Ana, Cindy and Ange attended evening events organised by Gates Ventures, EPND and AD-Riddle.

On 19 July (Amsterdam, Netherlands), Jean attended a meeting of the International Scientific Advisory Board of the Amsterdam Alzheimer Center.

On 19 July, Daphné and Soraya facilitated a small group discussion with online attendees of the AAIC.

On 20 July, Angela participated in a joint meeting of the EMA Patients' and Consumers' Working Party and FDA Patient Engagement Collaborative.

On 26 July, Dianne and Ana participated in a consultation with the company Evidera involving carers of the EDCWG and of the EWGPWD.

On 7 and 8 August (Helsinki, Finland), Jean, Gwladys and Cristina organised a field visit for the 33rd Alzheimer Europe Conference.

On 24 August (London, UK) Ana attended a pre-kick off meeting for a new IHI-funded project.

On 28 August, Dianne and Ana attended a meeting with representatives of Evidera.

On 29 August, Dianne and Daphné attended a meeting about WP4 for PROMINENT.

EU PROJECTS

5-6 June: LETHE project consortium meeting highlights innovative solutions for cognitive decline prevention

On 5 and 6 June, the LETHE project, a European initiative aiming to develop and test a multidomain intervention program for the prevention of cognitive decline in older adults, held its consortium meeting in Bologna, Italy. The meeting provided an opportunity for the partners to share the main results achieved so far, the progress of work, and the plan for the next 12 months of project activities.

Among the key topics discussed during the meeting, the following stood out:

- The design of the LETHE Robot and Audio Glasses Sub-studies, which will kick off at the end of the year. The aim is to test new interaction technologies with the target population, namely the Temi robot and BOSE audio glasses, to perform the LETHE protocol. These technologies are expected to enhance the user experience and engagement with the intervention program, as well as provide personalized feedback and support.
- An AI-driven risk stratification model that assesses the risk of cognitive decline in older adults. This model enables the identification of individuals with a high risk of cognitive decline at the start of a multidomain intervention program. By utilizing explainable AI techniques, we can examine the practicality of generating personalized risk profiles that offer valuable insights into individual risk and protective factors at the participant level. This approach represents an initial stage towards implementing an AI-driven personalized pathway for multidomain interventions within LETHE.

The meeting also featured the presentation of a knowledge base. Its purpose is to leverage the knowledge graph, which significantly connects data similar to how humans perceive and understand knowledge. This effectively simplifies the ability to discover information from analysed data. The formalization of "relations" between "entities" through graphs allows data scientists to conduct entity analysis, link analysis, network analysis, and statistical analysis.

- Additionally, the meeting showcased the first release of the Brain Health literacy Portal and the Multilanguage video generation solution. These include a web and mobile accessible portal and a content generation tool, aimed at engaging end users and increasing health literacy regarding the main risk factors impacting cognitive decline. The portal will provide evidence-based information and recommendations on how to maintain a healthy brain, while the video generation solution will allow users to create multilingual videos on brain health topics using text-to-speech and speech-to-text technologies.

Dr Sten Hanke, the LETHE project coordinator from FH JOANNEUM University for Applied Sciences, expressed his satisfaction with the outcomes of the meeting and thanked all the partners for their contributions. He also stressed the importance of continuing to work together towards the common goal of preventing cognitive decline and promoting healthy aging in Europe.

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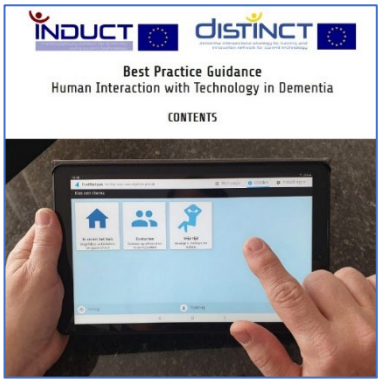
3 July: INDUCT and DISTINCT update their "Best Practice Guidance - Human Interaction with Technology in Dementia"



INDUCT (European Interdisciplinary Network for Dementia Using Current Technology) and DISTINCT (Dementia: Intersectional Technology for Training and Innovative Network for Current Technology) published an updated version of their Best Practice Guidance – Human Interaction with Technology in Dementia. This is a comprehensive set of recommendations on improvement of technology for people with dementia in three areas: everyday life, meaningful activities and healthcare. It also provides evidence to show how technology can improve the lives of people with dementia.

This Best Practice Guidance originally results from literature studies and field research conducted within INDUCT (2016-2020), a Marie Sklodowska Curie funded Innovative Training Network (ITN) of researchers at eight Universities in six European countries. DISTINCT supports fifteen Early Stage Researchers (ESRs) across Europe, who are carrying out research projects aiming to improve the lives of people with dementia and their carers through technology. The web-based version of the Best Practice Guidance was launched in autumn 2019 and each year since, an update has been published

(December 2020, December 2021, December 2022, and the latest update in June 2023).

The recommendations for improving the usability, effectiveness and implementation of technology in dementia, which are presented in this Best Practice Guidance, are meant to be helpful for different target groups: People with dementia; their formal and informal carers; health care and welfare providers; policymakers; designers and researchers. For this reason, representatives of these target groups were consulted and involved throughout the INDUCT and DISTINCT projects.

Alzheimer Europe is a partner in both INDUCT and DISTINCT.

The PDF of the updated guidelines is available here: https://www.dementiainduct.eu/wp-content/uploads/2023/06/D6.2-D6.5-BPG-website-format-update-15-6-2023-v6.2-FINAL.pdf

You can also explore the website and navigate to the recommendations relevant to you, here:

https://www.dementiainduct.eu/guidance/

4 July: Data from the AMYPAD Prognostic study is now publicly available

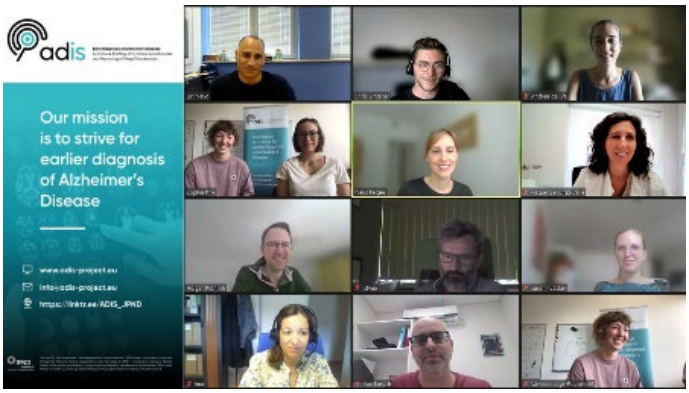
The AMYPAD consortium, in its partnership with Aridhia and ADDI, is delighted to announce the external data release of its Prognostic and Natural History Study (PNHS). The study was established to collect amyloid PET scans in a large-scale population and included participants from 11 European parent cohorts of similar characteristics in a predementia phase.

The integrated dataset represents the largest European PET dataset phenotyping longitudinally individuals at risk of Alzheimer's disease (AD)-related progression. The public dataset has been incorporated into the AD Workbench of the Alzheimer's Disease Data Initiative (ADDI), which is an open, global and free cloud-based platform for scientists to accelerate discoveries and innovations for AD and related dementias. To access the data, you will need to make an online request via the AD Workbench.

The current dataset includes a total of 3,368 participants. Of them, 1,620 underwent a baseline amyloid PET that includes the visual read and the Centiloid quantification (1,476 subjects), among other metrics. The participant's clinical outcomes (e.g., cognition), disease (imaging) biomarkers, risk factors (e.g., genetics and environmental), and other relevant variables are included in the dataset. The dataset is planned to be further expanded, both in terms of parent cohorts and in available data (e.g. quantification of advanced MRI sequences, genetics, blood biomarkers, etc.). For more information about the dataset and how to access to the date, visit the project's website:

https://amypad.eu/news/recent-news/data-from-amypad-pnhs-is-now-available-on-the-ad-workbench/

6 July: Advancing Alzheimer's Research: Insights and Collaborations from ADIS Consortium Meeting"



On July 6, 2023, the partners of the ADIS project held a consortium meeting to discuss the progress of their research. The meeting had two parts, one in the morning and one in the afternoon. Various topics were discussed, including project management, dissemination and outreach, experimental approaches, data collection, modelling, public involvement, and future applications.

The meeting began with opening remarks by the project coordinator, Prof. Holger Fröhlich, who emphasized the importance of collaboration and thanked the consortium members for their contributions. Vanessa Lage-Rupprecht and Chris Bintener presented updates on project management, dissemination, and outreach efforts. They highlighted the project's milestones and its impact on the wider community.

Andrea del Val Guardiola led the discussion on experimental approaches and data collection. She covered ethics protocols, acquisition of clinical data and biosamples, immune profiling, and single-cell sequencing. The enrolment of participants in the ADIS study was also discussed. Sophia Krix presented on agent-based modelling and its application to study the dynamics of Alzheimer's disease. The potential applications and challenges of this modelling approach were discussed.

After a lunch break, the meeting resumed with further discussions on modelling, focusing on AI and statistical modelling. Sophia Krix elaborated on the use of these advanced techniques to gain a deeper understanding of Alzheimer's disease and its progression. The session then shifted to patient and public involvement, led by Ana Diaz. The opinions and values of people with dementia were discussed, along with the involvement of the Advisory Board. The importance of incorporating the perspectives of individuals with AD was highlighted. The consortium also discussed a review paper that is currently being drafted and explored future applications and projects. This session fostered collaboration and innovative thinking.

The meeting concluded with a wrap-up session where key takeaways were summarized, and appreciation was expressed for the productive discussions. The next General Assembly meeting is scheduled for January 16-18 in Barcelona, Spain.

7 July: Paper on ethical challenges of using remote monitoring technologies for clinical research published by RADAR-AD and co-authored by Alzheimer Europe

A new RADAR-AD consortium paper, "Ethical challenges of using remote monitoring technologies for clinical research: A case study of the role of local research ethics committees in the RADAR-AD study" was published in the journal PLOS ONE on 7 July 2023.

Clinical research with remote monitoring technologies (RMTs) has multiple advantages over standard paper-pencil tests, but also raises several ethical concerns. While several studies have addressed the issue of governance of big data in clinical research from the legal or ethical perspectives, the viewpoint of local research ethics committee (REC) members is underrepresented in the current literature. The aim of this study was therefore to find which specific ethical challenges are raised by RECs in the context of a large European study on remote monitoring in all syndromic stages of Alzheimer's disease, and what gaps remain.

Documents describing the REC review process at 10 sites in 9 European countries from the project Remote Assessment of Disease and Relapse–Alzheimer's Disease (RADAR-AD) were collected and translated. Main themes emerging in the documents were identified using a qualitative analysis approach.

Four main themes emerged after analysis: data management, participant's wellbeing, methodological issues, and the issue of defining the regulatory category of RMTs. Review processes differed across sites: process duration varied from 71 to 423 days, some RECs did not raise any issues, whereas others raised up to 35 concerns, and the approval of a data protection officer was needed in half of the sites.

The differences in the ethics review process of the same study protocol across different local settings suggest that a multi-site study would benefit from a harmonisation in research ethics governance processes. More specifically, some best practices could be included in ethical reviews across institutional and national contexts, such as the opinion of an institutional data protection officer, patient advisory board reviews of the protocol and plans for how ethical reflection is embedded within the study.

Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz are co-authors of this paper.

The paper is available here:

https://doi.org/10.1371/journal.pone.0285807

Further information on RADAR-AD is available from the project website:

https://www.radar-ad.org/

16 July: World Wide FINGERS Network Meeting takes place at AAIC in Amsterdam

On 16 July 2023, at the Alzheimer's Association International Conference (AAIC) in Amsterdam, the World Wide FINGERS (WW-FINGERS) network held a meeting, hosted by the Alzheimer's Association. WW-FINGERS is an interdisciplinary network created to share experiences, harmonise data and methods and to support and convene global multidomain dementia prevention trials. Professor Miia Kivipelto, founder and scientific lead of the WW-FINGERS Network, welcomed the 113 in-person and 32 virtual attendees, including WW-FINGERS investigator teams from around the world. Following her introduction, representatives of these teams of investigators shared their exciting achievements regarding multi-domain interventions in Canada, Finland, Ireland, Japan, Latin America, the Netherlands, South Korea, Sweden, the United Kingdom and the US.

Jean Georges, Executive Director of Alzheimer Europe represented the EU-FINGERS project at the WW-FINGERS Network Meeting.

16 July: EU-FINGERS features prominently at #AAIC23

The 2023 Alzheimer's Association International Conference (AAIC) took place from 16-20 July as a hybrid event (online and in Amsterdam, Netherlands). A key session of the event was dedicated to Patient and Public Involvement (PPI) in dementia research. Several members of the EU-FINGERS team were in attendance to present the EU-FINGERS approach. First, Anna Rosenberg (Finnish Institute for Health and Welfare) and Cindy Birck (Alzheimer Europe) described the main principles, challenges and approach used to set up the Advisory Board, led by Alzheimer Europe. "For the very first time, we set up a group composed of people at different stages across the AD continuum. The EU-FINGERS Advisory Board is a successful example of involvement of several people willing to share their views, consisting of 14 members from 7 EU countries. We built an environment where people feel safe and confident to share opinions." *said Cindy Birck*

Next, Heleen M.A. Hendriksen (Alzheimer Center Amsterdam) presented some of the work developed with the Advisory Board, specifically on the important topic of communication in this complex field. This includes reflections on the terminology to discuss the topic of risk reduction and dementia prevention in different contexts, as well as the more specific topic of dementia risk communication in the context of the memory clinic. The latter is an example of one of the tools which the consortium is developing.

To close the talk, Nick Montague (Luxembourg) shared his experience as a member of the EU-FINGERS Advisory Board. He mentioned his diagnosis and his daily routine. He also addressed the value of the Advisory Board and this type of work. "For me this is a very trusted and safe environment where I can say honestly, what I think. I find that being part of this group discussing various parts of dementia is very worthwhile challenging and hopefully helpful to the researchers." said Nick Montague.

16 July: EPND project featured at AAIC conference in Amsterdam

The 2023 Alzheimer's Association International Conference (AAIC) drew over 7,000 delegates to Amsterdam, with more than 3,000 presentations delivered by global experts on disease mechanisms, biomarkers, diagnosis, treatment and care. The European Platform for Neurodegenerative Diseases (EPND) was well-represented at AAIC, with poster presentations and a guest feature at the exhibition stand of the Alzheimer's Disease Data Initiative (ADDI).

EPND's mission is to accelerate the discovery of diagnostics and treatments for neurodegenerative disorders such as Alzheimer's and Parkinson's disease, by removing barriers to data and sample sharing, and by fostering collaboration. In particular, EPND aims to facilitate the discovery, development and validation of biomarkers, biological molecules that are measurable indicators of processes happening inside the body, such as the development of disease. To achieve these aims, EPND is developing a platform that will support the discovery and sharing of clinical data and biosamples from European research cohorts.

At AAIC, Pieter-Jelle Visser, Professor of Molecular Epidemiology of AD at the University of Maastricht, and co-Coordinator of EPND, gave a poster presentation explaining how the project is removing barriers to data and sample sharing, and fostering collaboration. In his presentation, he highlighted an important new development for EPND: the launch of the Cohort Catalogue, which brings together information on 69 research cohorts involving 180,825 research participants. To ensure the Cohort Catalogue would be as useful as possible, a vast array of metadata for each cohort was incorporated, Prof. Visser explained, providing researchers with a single location to easily search – and discover – the complete landscape of neurodegenerative disease cohorts across Europe, and beyond.

EPND partner Marina Boccardi, Professor of Implementation Neuroscience at the University of Rostock, presented a poster on the use of Target Product Profiles (TPP) in academic research. TPPs are widely used in industry, to address, define and communicate user needs in the drug development process. In her systemic review, carried out as part of the sustainability workstream in EPND, Prof. Boccardi identified a large number of publications on TPPs for infectious diseases, but found that these useful tools are rarely used in dementia research.

To learn more about EPND, visit the project website: https://epnd.org/

2 August: Paper on "Precision medicine in neurodegeneration" published by IHI-PROMINENT project

On 2 August, a new paper was published in the journal Frontiers in Neurology, discussing the recently-launched IHI-PROMINENT project. Alzheimer Europe is a partner in the project, leading on communications, stakeholder engagement and public involvement activities and Executive Director Jean Georges is a co-author of this paper.

The published paper centres on the fact that neurodegenerative diseases drive elderly morbidity and mortality. In Europe, 14 million people are estimated to be living with dementia, costing an approximated EUR 400 billion annually. Recent diagnostic and pharmaceutical strides in Alzheimer's disease (AD) hint at precision medicine's rise and potential usefulness. However, strained healthcare systems need innovative digital solutions for personalized care via clinical pathways. Public-private partnerships shine here. The IHI-PROMINENT project, an Innovative Health Initiative funded endeavour unites researchers, medical centres, patients as well as patient organisation Alzheimer Europe, and technology for precision care. It builds on collaborative digital tools, targeting early AD detection, diagnosis, and monitoring. From diagnosis

to treatment, the project aims at better cost-effective care and improved outcomes. You can read the paper here:

https://doi.org/10.3389/fneur.2023.1175922

5 August: New EU-FINGERS and LETHE paper out on communication in memory clinic settings

There is now compelling evidence that Alzheimer's disease (AD) takes hold in the brain decades before dementia symptoms appear, providing a window of opportunity for preventative efforts to stop the disease before the onset of dementia. Today's research increasingly involves the whole continuum, including the earlier stages of the disease. This is accompanied by increasing numbers of patients in pre-dementia stages visiting the memory clinic with a strong need for information about their current disease or health status and the consequences for their daily life. This paradigm shift towards earlier AD stages and personalised medicine creates new challenges for clinician-patient communication. It can both be difficult for the clinician to communicate about AD biomarker results and dementia risk and for the patient to understand the message.

New research published in the journal Alzheimer's Research & Therapy investigated the opinions of European memory clinic professionals on communicating about (etiological) diagnosis, prognosis, and prevention with patients and their care partners in the memory clinic. This study was conducted in the context of the EU-FINGERS and LETHE projects.

160 memory clinic professionals from 21 European countries completed an online survey, consisting of four parts: (1) characteristics, (2) statements, (3) patient cases, and (4) needs and preferences for communication support. The majority of professionals agreed that communication on diagnosis, prognosis, and prevention should be personalised to the individual patient. However, professionals differed in how they would explain the meaning of (ab)normal biomarker results to patients, depending on their disease stage. In addition, the majority of clinicians would appreciate communicating skills training or online tools to support them in these complex conversations. These findings can inform the (further) development of such tools and communication skills training programs, and aid the implementation process.

Congratulations to all authors: Heleen M. A. Hendriksen, Aniek M. van Gils, Argonde C. van Harten, Tobias Hartmann, Francesca Mangialasche, Anita Kamondi, Miia Kivipelto, Hanneke F. M. Rhodius-Meester, Ellen M. A. Smets, Wiesje M. van der Flier and Leonie N. C. Visser! You can read the paper here:

https://doi.org/10.1186/s13195-023-01276-9

8 August: Pattern-Cog project publishes its first newsletter

On 8 August, the Pattern-Cog project released its first external newsletter. Pattern-Cog is a multinational interdisciplinary consortium aiming to improve dementia prevention strategies by developing support tools for the detection of earliest signs of impeding cognitive decline which would allow early and personalised multidomain interventions. Funded by ERA PerMed, the three-year project includes six partners from five European countries

The newsletter provides readers with the latest project updates including the important advances and major achievements made by each Work Package. The newsletter covers work of the Advisory Board, composed of the members of the European Dementia Carers Working Group (EDCWG). This issue also features interviews with two Pattern-Cog members Christian Gaser from the University of Jena in Germany and Soraya Moradi-Bachiller from Alzheimer Europe.

You can read the newsletter here:

https://mailchi.mp/8d4d8763f978/pattern-cog-newsletter-august-2023

EU project acknowledgements

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PatternCog - This project is supported by the Luxembourg National Research Fund (INTER/PerMed21/15748787/Pattern-Cog), under the frame of ERA PerMed.

Members of the European Alzheimer's Alliance

Currently, the total number of MEPs in the Alliance stands at **87**, representing **26** out of 27 Member States of the European Union and seven out of seven political groups in the European Parliament. Alzheimer Europe would like to thank the following MEPs for their support of the European Alzheimer's Alliance (EAA):

Austria: Claudia Gamon (Renew Europe); Monika Vana (Greens/EFA). **Belgium**: Frédérique Ries (Renew Europe); Kathleen van Brempt (S&D); Hilde Vautmans (Renew Europe). **Bulgaria**: Radan Kanev (EPP); Andrey Kovatchev (EPP); Ilhan Kyuchyuk (Renew Europe); Tsvetelina Penkova (S&D); Sergei Stanichev (S&D). **Croatia**: Biljana Borzan (S&D); Tonino Picula (S&D). **Cyprus**: Costas Mavrides (S&D). **Czech Republic**: Tomáš Zdechovský (EPP). **Denmark**: Margrete Auken (Greens/EFA); Christel Schaldemose (S&D). **Estonia**: Urmas Paet (Renew Europe); **Finland**: Alviina Alametsä (Greens/EFA); Heidi Hautala (Greens/EFA); Miapetra Kumpula-Natri (S&D); Sirpa Pietikäinen (EPP). **France**: François-Xavier Bellamy (EPP); Dominique Bilde (I&D); Nathalie Colin-Oesterlé (EPP); Arnaud Danjean (EPP); Geoffroy Didier (EPP); Agnes Evren (EPP); Sylvie Guillaume (S&D); Brice Hortefeux (EPP); Nadine Morano (EPP); Dominique Riquet (Renew Europe); Anne Sander (EPP). **Germany**: Alexandra Geese (Greens/EFA); Erik Marquardt (Greens/EFA); Angelika Niebler (EPP); Terry Reintke (Greens/EFA). **Greece**: Manolis Kefalogiannis (EPP); Stelios Kouloglou (GUE/NGL); Dimitrios Papadimoulis (GUE/NGL); Maria Spyraki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary**: Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland**: Barry Andrews (Renew Europe); Deirdre Clune (EPP); Ciarán Cuffe (Greens/EFA), Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Grace O'Sullivan (Greens/EFA). **Italy**: Isabella Adinolfi (EPP); Brando Benifei (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania**: Vilija Blinkeviciute (S&D). **Luxembourg**: Marc Angel (S&D); Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens/EFA); Isabel Wiseler-Lima (EPP). **Malta**: Roberta Metsola (EPP); Alfred Sant (S&D). **Netherlands**: Jeroen Lenaers (EPP); Annie Schreijer-Pierik (EPP). **Poland**: Elzbieta Lukacijewska (EPP); Jan Olbrycht (EPP). **Portugal**: Sara Cerdas (S&D); José Gusmão (GUE/NGL); Marisa Matias (GUE/NGL); Clàudia Monteiro de Aguiar (EPP). **Romania**: Cristian-Silviu Busoi (EPP); Marian-Jean Marinescu (EPP). **Slovakia**: Ivan Stefanec (EPP). **Slovenia**: Franc Bogovič (EPP); Milan Brglez (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (Renew Europe); Romana Tomc (EPP); Milan Zver (EPP). **Spain**: Izaskun Bilbao Barandica (Renew Europe); Rosa Estaràs Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens/EFA); Ernest Urtasun (Greens/EFA). **Sweden**: Peter Lundgren (ECR).

EU DEVELOPMENTS

1 July: Spain assumes rotating Presidency of the Council of the EU

On 1 July, Spain assumed the Presidency of the Council of the EU and will continue in the role until 31 December 2023. There are four key priority areas for the work of the Presidency during its term including, including:

- Re-industrialising the EU and ensure its open strategic autonomy
- Advancing the green transition and the environmental adaptation
- Promoting greater social and economic justice
- Strengthening European unity.

The Spanish Presidency highlights that the there is a need to improve opportunities and living standards for European citizens. As part of this, workers' rights in several areas and for vulnerable groups such as children, women suffering from violence and people with disabilities will be a focus for its work.

In addition, the Presidency also commits Spain to working for the European Health Union, noting that the EU cannot be successful without guaranteeing citizens' health. More information is available at the Spanish Presidency website at:

https://spanish-presidency.consilium.europa.eu/en/

1 July: European Economic and Social Committee welcomes applications for the 14th EESC Civil Society Prize

On 1 July 2023, the European Economic and Social Committee (EESC) opened applications for the 14th EESC Civil Society Prize. The prize will reward effective, innovative and creative initiatives carried out on the territory of the European Union (EU) which support people with mental health conditions and promote an environment fostering mental well-being on an individual or collective basis.

It is open to non-for-profit initiatives carried out by natural persons, civil society organisations and private companies officially registered within the EU. It has a total value of EUR 50,000 and can be shared among up to five winners.

The aim of the award is to raise awareness of the contribution that civil society can make to promoting a European identity and citizenship in a way that underpins the common values that are the foundation of European integration.

The deadline for submitting applications is 30 September 2023 (10:00 a.m. CEST).

For further information, email: civilsocietyprize@eesc.europa.eu

The application form is here.

Further information can be found, here.

1 July: The European Medicines Agency hosts Patients' and Consumers' Working Party meetings

On 27 and 28 June, the European Medicines Agency (EMA) hosted meetings for its Patients and Consumers Working Party (PCWP) in Amsterdam. Alzheimer Europe is a member of the PCWP, which is composed of over 40 patient organisations and NGOs from across Europe.

The PCWP plenary, which was organised on 27 June, focused on two main topics: operation of the PCWP, and EMA communications. During the first half of the PCWP meeting, Giulia Gabrielli from the EMA Public and Stakeholders Engagement department presented the results of a recent PCWP satisfaction survey, which was circulated in May 2023. Next, Maria Mavris (EMA Patient relations lead) and Angela Bradshaw (Project Officer at Alzheimer Europe) spoke about ways to enhance interactions between the agency and PCWP members. This was followed by a lively discussion between EMA representatives and PCWP members – the majority of which are umbrella organisations and NGOs – on ways to increase collaborative engagement of the PCWP with EMA activities. The second half of the PCWP plenary was focused on EMA communications. Monika Benstetter of EMA spoke about strategies to combat disinformation and misinformation, drawing on lessons learned from the COVID-19 pandemic. The spread of false messages supported polarisation of the public debate on vaccines, she explained, outlining how EMA actively combated misinformation through live streams, information campaigns and online resources. Continuing the communications theme, Christopher Gadd then presented the results of a stakeholder survey on EMA communications, which identified areas for improvement such as increasing the use of visual materials and providing translations.

The joint meeting of the PCWP and HCPWP (Healthcare Professionals' Working Party) was held the next day, on 28 June. The first half of the meeting was dedicated to ongoing EMA activities, featuring talks from EMA experts on real-world data initiatives, electronic patient information forms, preparedness for public health emergencies, medicines shortages and patient experience data. Input and feedback was sought from PCWP and HCPWP members during Q&A sessions following each presentation. In the afternoon, the focus shifted to pharmacovigilance, clinical trials, and communications. Experts from the Pharmacovigilance Risk Assessment Committee described how the outer packaging of opioid-containing medications will be adapted in light of safety and addictions concerns, and representatives from the Danish and Dutch authorities spoke about decentralised clinical trials; studies which occur at locations other than traditional clinical trial sites. Closing the meeting, Juan Garcia Burgos (Head of the Public Engagement Department and co-Chair of the PCWP and HCPWP) summarised key discussion points and thanked all participants, highlighting the upcoming PCWP and HCPWP meetings in the autumn. Access the meeting agenda and presentations: here and here

4 July: European Commission launches European Accessibility Resource Centre

As part of its Strategy for the Rights of Persons with Disabilities 2021-2030, the European Commission has launched the European Accessibility Resource Centre (AccessibleEU) to increase coherence in accessibility policies and facilitate access to relevant knowledge.

AccessibleEU is intended as a common European one-stop-shop on accessibility offering experience, knowledge and practical skills for a range of actors including policymakers, legislators and the representatives of accessibility beneficiaries. Its focus will be on training, raising awareness, disseminating good practices, promoting the development of standards on accessibility, as well as managing knowledge and mutual learning among public, for-profit and civil society actors.

Finally, AccessibleEU will connect dispersed knowledge, to support the obligation of transposing EU legislation, creating a

cross-European community of practice of accessibility professionals.

More information on the Resource Centre is available at:

https://ec.europa.eu/social/main.jsp?catId=1612&langId=en

2 August: UN Human Rights representatives propose amendments to Commission proposals

Two UN representatives on human rights have made a joint submission in response to the European Commission's proposal for a Regulation on cross border legal arrangements and a Council Decision governing the Hague Convention on the Protection of Adults.

In their submission, the UN Special Rapporteur on the Rights of Persons with Disabilities and the UN Independent Expert on the Enjoyment of All Human Rights by Older Persons welcome efforts to resolve issues around cross border application of law, as well as references to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in the recitals of the legislation.

However, their submission also highlights where the legislative proposals and the Hague Convention, and the UNCRPD are incompatible, including issues in Article 3 around supported decision-making and placement in institutions outlined in Article 21.

They also highlight a 2021 legal study on the Hague Convention commissioned by the Special Rapporteur, which recommended that countries becoming party to the 2000 Hague Convention should adopt a declaration saying that it would interpret and apply the Hague Convention in line with the UNCRPD. In relation to the Council Decision, the representatives commend this approach, as well as a making a Reservation to the Hague Convention, excluding institutionalisation from its scope. The full joint submission of the rapporteurs can be read at:

https://www.ohchr.org/sites/default/files/documents/issues/disability/olderpersons/Annex-Joint-Submission-Towards-Greater-Coherence-International-Law.pdf

POLICY WATCH

6 July: Slovenian Government approves new national dementia strategy until 2030

On 6 July 2023, the Government of the Republic of Slovenia approved the new Strategy for Dementia Management in Slovenia until 2030. This is a significant step and achievement for people with dementia and their carers and it is also an important development for tackling dementia in Slovenia as a whole. The adoption of this new strategy means the implementation of the goals it sets out can begin.

Spominčica (Alzheimer Slovenia) was the initiator of the country's first ever national dementia strategy, which they started working on in 2010. That strategy expired in 2020. Spominčica has been a very active member of the working group for the preparation of this second strategy, which will run until 2030. The working group began preparing the new strategy back in 2019, not long after which the COVID-19 pandemic struck, leading to a long delay in the proceedings to prepare and adopt the new document.

At the launch of the strategy, on 6 July 2023, Tadej Ostrc (pictured) State Secretary at the Ministry of Health, highlighted that the main goals of the document focus on long-term care for people with dementia and, above all, on support for families and carers in their local areas and home environments.

https://siol.net/novice/slovenija/vlada-o-obvladovanju-demence-in-ustanovitvi-nacionalnega-centra-za-demenco-610702

31 July: CEAFA disappointed by total lack of measures on dementia in manifestos of main political parties during Spanish general elections

In the run-up to the Spanish general election of 23 July 2023, the Confederación Española de Alzheimer (CEAFA) – the Spanish Confederation of Alzheimer's and other dementias – released a statement, on 19 July, highlighting that it was disappointed that measures related to the growing problem of Alzheimer's disease (AD) and other types of dementia were a glaring omission from the political agenda, with a clear lack of such measures in the manifestos of the main political parties. There was not even a mention of either "Alzheimer's" or "dementia" in any of these manifestos.

Almost five million people live with AD or other types of dementia in Spain and, according to data from the Spanish Neurology Society, every year some 40,000 new cases are diagnosed. On top of this, it is estimated that 80% of those that are still in the early stages of the disease remain undiagnosed, making this a vital and urgent problem to tackle.

CEAFA argued that continuing to postpone measures to lessen the impact of dementia could have serious social, health and economic consequences, and suggested addressing dementias as a social and health priority of the first magnitude, with appropriate responses, shaping methodologies and strategies for intervention and interdisciplinary coordination, in order to move towards more comprehensive and dementia-friendly society and environment.

Finally, CEAFA urged the different political groups to re-evaluate their health and social policies and encouraged them to include in their proposals coverage and protection systems, as well as measures to promote biomedical and social research that could offer a cure for AD and improve quality of life for people with this and other types of dementia.

30 August: World Health Organization Quality Rights initiative invites you to help shape the future of dementia services by identifying good practices with a person-centred approach

The World Health Organization (WHO) Quality Rights initiative is working to improve access to quality mental health services globally and to promote the human rights of people with mental health conditions and psychosocial, intellectual, and cognitive disabilities. As part of this initiative, it is developing a good practice guidance document which will present information on dementia services that promote human rights and the recovery approach. This is also in support of WHO's global mandate - the Global action plan on the public health response to dementia 2017-2025 (WHA A70/28).

The initiative is seeking support to identify people-centred services that operate without coercion, and that respond to people's needs by promoting autonomy, inclusion in the community, and the involvement of people with lived experience at all levels of decision-making. This should include services that support people experiencing acute crises but that do not resort to force, coercion, involuntary admission and treatment or the use of seclusion and restraints.

If you would like to help them in their search, please complete the survey below. By completing the questionnaire, you will have the opportunity to submit any dementia services that you believe should be considered as a good practice and can therefore potentially contribute to shaping the future of mental health services. Anyone who is involved in providing a service, has experience of using a service, or knows of a service is welcome to complete the questionnaire and you can submit as many services as you wish.

This online consultation survey will close on 31 October 2023 at 23:45 GMT.

https://nottingham.onlinesurveys.ac.uk/dementia-service-identification-questionnaire

AAIC WATCH

We present some highlights emerging from this year's Alzheimer's Association International Conference (AAIC), held in Amsterdam and online from 16 to 20 July 2023:

16 July: Proposal for revised clinical criteria for Alzheimer's disease diagnosis presented at AAIC

In 2018, the National Institute on Aging and the Alzheimer's Association (NIA-AA) published a research framework for Alzheimer's disease classification based on biomarkers, which are biological indicators of disease that can be measured by cerebrospinal fluid (CSF) tests, brain scans, and other assays. The 2018 framework was designed to support the classification of Alzheimer's disease in the context of research studies, not general clinical work. However since then, scientific advances have propelled the Alzheimer's disease field forwards, with the development of blood-based biomarkers and the regulatory approval of new PET tracers and CSF tests.

At a special symposium during the Alzheimer's Association International Conference (AAIC), the NIA-AA Work Group released a draft update to the 2018 research framework, extending it to criteria for diagnosing Alzheimer's disease in the clinic. These revised guidelines incorporate fluid and imaging biomarkers in a clinical framework for diagnosing Alzheimer's disease (AD). The 2023 update distinguishes clinical symptoms such as memory loss from the biological causes of AD – such as amyloid plaques and tau tangles, which can be measured using a range of blood, CSF and imaging biomarkers.

Core principles of the Framework state that:

- AD is defined by its biology, and is first evident when people are asymptomatic, but have amyloid plaques and tau tangles in the brain; and
- Clinical symptoms, such as memory problems, are not necessary to diagnose AD, which can be diagnosed using disease-specific biomarkers.

To support the biological diagnosis, staging and prognosis of AD, the updated guidelines identify specific fluid and imaging biomarkers that can be used to determine whether patients are at the initial, early, intermediate or advanced biological stage of AD. Core biomarkers for AD are those that directly connected to amyloid or tau, which are identified as the defining biological drivers of AD. For example, someone at the initial biological stage of AD might have a positive amyloid PET scan and a negative tau PET scan, or a positive blood test for the biomarkers pTau181 or pTau217. The guidelines also include a framework for the clinical staging of patients based on symptoms, with clinical stage 1 being asymptomatic but with biomarker positivity, and clinical stage 6 being AD dementia with severe functional impairment. An integrated biological and clinical staging framework incorporates both biological and clinical parameters, providing classifications for patients at different stages of AD. For example, a patient at stage 2b would have some subtle symptoms of cognitive decline (clinical stage 2) with biomarkers that indicate an "early biological stage" (biological stage b).

This represents a paradigm shift for the clinical diagnosis of AD, which is most frequently diagnosed in the symptomatic stages using tests for cognition or executive function alongside physical examinations and evaluation of the patients' medical history. The NIA-AA Work Group, which is chaired by Clifford Jack of the Mayo Clinic and includes 21 other experts from

academic institutions, regulatory agencies, Alzheimer's Associations and industry, hopes that the updated framework will support earlier, more accurate diagnosis and swifter access to treatments and clinical trials. The framework will be available for public comment on the Alzheimer's Association website until 16 August.

Read the revised clinical guidelines: https://aaic.alz.org/nia-aa.asp#workgroup

17 July: Results from Lilly's TRAILBLAZER-ALZ2 clinical trial of donanemab presented at AAIC and published in JAMA

On 17 July 2023, at the Alzheimer's Association International Conference (AAIC) in Amsterdam, Netherlands, Eli Lilly and Company (Lilly) presented the full results of its TRAILBLAZER-ALZ2 randomised clinical trial looking at whether the drug donanemab provides clinical benefit in early symptomatic Alzheimer's disease (AD). TRAILBLAZER-ALZ 2 assessed the safety and efficacy of donanemab, a monoclonal antibody designed to clear brain amyloid plaques. Topline results were announced in a company press release earlier in the year (3 May), and the full trial results were shared at AAIC during a featured symposium and simultaneously published in the Journal of the American Medical Association (JAMA).

TRAILBLAZER-ALZ 2 was a global phase III placebo-controlled, double-blind, parallel-group and randomised study which enrolled 1,736 people with mild cognitive impairment due to AD or mild AD dementia, with confirmed accumulation of amyloid and tau proteins in the brain. Participants from Australia, Canada, Europe, Japan and US received either donanemab or a placebo, via a monthly intravenous infusion. Lilly previously announced that donanemab met the primary and all cognitive and functional secondary endpoints in the phase III study.

Topline results revealed that the study met its primary endpoint at 18 months (76 weeks). In participants with early symptomatic AD and amyloid and tau pathology, results showed that donanemab treatment significantly slowed clinical progression, using the global cognitive and functional scale, iADRS, which showed a 22% reduction in decline for all participants receiving donanemab compared to those receiving placebo. Lilly highlighted that the primary analysis population, 1,182 participants with intermediate levels of tau in the brain, had a 35% reduction in clinical decline on the iADRS scale. These individuals were at an earlier stage of disease progression, relative to the 552 participants with high levels of brain tau at baseline.

Additional data presented at AAIC reinforced that, regardless of baseline clinical or pathological stage of disease, treatment with donanemab resulted in cognitive and functional benefits relative to placebo:

- A pre-specified subpopulation analysis of low-medium tau participants based on clinical stage showed greater benefit of donanemab in those at earlier stage of disease:
    - In 214 participants with mild cognitive impairment, donanemab slowed decline by 60% on iADRS and 46% on CDR-SB. In comparison, for 534 participants with mild dementia due to AD, donanemab slowed decline by 30% on iADRS and 38% on CDR-SB, respectively.
- Similarly, a post-hoc subgroup analysis of low-medium tau participants based on age showed greater benefit of donanemab in patients under the age of 75:
    - In 542 participants under the age of 75, donanemab slowed decline by 48% on iADRS and 45% on CDR-SB.
    - In 551 participants aged 75 or greater, donanemab slowed decline by 25% on iADRS and 29% on CDR-SB.
- Results were similar across other subgroups, including participants who carried or did not carry an allele of the ApoE4 gene.
- The overall treatment effect of donanemab continued to grow throughout the trial, with the largest differences versus placebo seen at 18 months.

Regarding the safety of the drug, the study found that amyloid-related imaging abnormalities (ARIA) were the most common side-effects of treatment. ARIA occur across the class of amyloid plaque-clearing antibody therapies and these findings were therefore consistent with other investigational therapies in the same class. The incidence of ARIA and infusion-related reactions was also consistent with the previous TRAILBLAZER-ALZ study. ARIA, which are detected using MRI scans, are most commonly observed as swelling in an area or areas of the brain (ARIA-E) or as brain microbleeds (ARIA-H). While many cases of ARIA are temporary or asymptomatic, ARIA can be serious and even fatal in some cases.

In the donanemab treatment group, brain swelling (ARIA-E) occurred in 24% of TRAILBLAZER-ALZ 2 participants. Brain microbleeds (ARIA-H) occurred in 31.4% of participants receiving donanemab, compared to 13.6% of participants on placebo. The majority of ARIA cases were mild to moderate, with 1.6% of participants experiencing serious ARIA. The company noted that this risk should be managed with careful observation, monitoring with MRIs, and appropriate actions if ARIA is detected.

Lilly has completed the US Food and Drug Administration (FDA) regulatory submission of donanemab and expects a decision by the end of 2023. Submissions to other global regulators are currently underway, with the company hoping to complete the majority of these by year end.

Alzheimer Europe welcomes the encouraging data presented at AAIC, where Executive Director Jean Georges was in attendance at the Lilly symposium, alongside Project Officer Cindy Birck.

Read the study in JAMA, here:

https://jamanetwork.com/journals/jama/fullarticle/2807533

Read the Lilly press release, here:

https://investor.lilly.com/news-releases/news-release-details/results-lillys-landmark-phase-3-trial-donanemab-presented

18 July: Hearing aids may reduce cognitive decline in older adults at risk of dementia, according to new findings presented at AAIC

Hearing loss was identified in the 2020 Lancet Commission as one of 12 modifiable risk factors that contribute to around 40% of dementia diagnoses worldwide. In a new article published in the Lancet, and simultaneously presented at the 2023 Alzheimer's Association International Conference, researchers from the ACHIEVE trial show that hearing aids may help reduce long-term cognitive decline in older adults with mild to moderate hearing loss.

ACHIEVE is a multicentre, parallel-group, unblinded, randomised controlled trial which recruited adults aged 70-84 years with untreated hearing loss and without substantial cognitive impairment. In total, 977 participants were recruited to ACHIEVE: 739 healthy volunteers, and 238 participants from the Atherosclerosis Risk in Communities (ARIC) study, a long-standing observational study of cardiovascular health. Participants were randomly assigned 1:1 to receive a hearing intervention (hearing aids and counselling from an audiologist), or sessions with a health educator on chronic disease prevention.

Analysis of ACHIEVE data showed there was little difference in outcomes on a comprehensive neurocognitive battery between participants receiving the hearing intervention and those who received the health education sessions. However, a prespecified sensitivity analysis on the ARIC participants, who had more risk factors for cognitive decline and lower cognition scores at baseline, revealed a 48% reduction in cognitive decline over 3 years in this group. This suggests that the hearing intervention was more beneficial for older adults at greater risk of cognitive decline, for example due to higher rates of hypertension or diabetes. A follow-up study of the ACHIEVE cohort is now underway, evaluating longer-term effects of the hearing intervention.

Read the AAIC press release:

https://aaic.alz.org/releases_2023/hearing-aids-slow-cognitive-decline.asp

Read the Lancet article:

https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(23)01406-X/fulltext#seccestitle150

18 July: New study investigates the link between use of opioids and risk of death in people with dementia

Opioids have been associated with an increased excess mortality-risk in the general population. Older people with dementia have been prescribed opioids more frequently and the use of strong opioids has increased considerably over the past decade among older people with dementia.

A new study presented at the Alzheimer's Association International Conference (AAIC) in Amsterdam (Netherlands) reported that new opioid use in older adults diagnosed with dementia is associated with a significantly increased risk of death.

The study included more than 75.000 Danish residents aged 65 years and older diagnosed with dementia between 2008 and 2018, including both home-living and nursing home residents. 42% of this study population diagnosed with dementia redeemed a prescription for an opioid at a pharmacy. The researchers followed study participants for 180 days after their first opioid prescription. They also followed a group of older adults with dementia who did not receive an opioid prescription and compared risk of death between the two groups.

Findings showed that new opioid use was frequent among older people with dementia and this was associated with a significantly increased risk of death. 33% of the study participants died within 180 days after initiating their first opioid prescription, compared with 6.4% of those with the disease who didn't take opioids.

After adjusting for potential differences between groups, researchers found a fourfold increased excess mortality risk. The risk was greatest in the first two weeks, where mortality for all opioids was increased elevenfold.

Strong opioids (i.e. morphine, oxycodone, ketobemidone, hydromorphone) were associated with a six-fold increased mortality risk, whereas the risk was lower for weak opioids.

Read the AAIC press release:

https://aaic.alz.org/releases_2023/opioids-increase-risk-death-older-adults-dementia.asp

19 July: Clinical study presented at AAIC finds a link between chronic constipation and cognitive decline in older adults

Constipation is more frequent in older adults, due to age-related factors such as lack of physical exercise, diets that may be low in fibre, and medicines for chronic conditions that can cause constipation. New research presented at AAIC last week indicates that chronic constipation may impact cognitive function as we age, revealing a potential link between the gut microbiome and brain health.

To study the relationship between constipation and cognitive decline in older adults, Dr Chaoran Ma of the University of Massachusetts studied data and samples from over 110,000 participants in three prospective, US-based cohort studies: the Nurses' Health Study, the Nurses' Health Study II, and the Health Professionals' Follow-up study. Participants in these cohorts undergo regular assessments of health and lifestyle factors, designed to understand risk factors for major chronic

diseases. Dr Ma's team collected information on bowel movement frequency in 2012-2013, as well as self-assessments of cognitive function in the ensuing 4 years; cognitive tests were also conducted between 2014 and 2018, in a subgroup of 12,696 participants. The gut microbiota of 515 men and women was profiled in faecal samples using a new technique called shotgun metagenomic analysis, which is able to identify the types of bacteria present in the gut.

Data analyses revealed that participants with chronic constipation (defined as bowel movements every 3+ days) were 73% more likely to report subjective cognitive decline. They also found a link between chronic constipation and poorer cognitive function based on objective tests, equivalent to an estimated 3 years of chronological cognitive aging compared to participants with regular, daily bowel movements. The researchers identified differences in gut microbiome composition in participants with chronic constipation, suggesting that those with fewer bacteria responsible for producing butyrate or digesting dietary fibre were more likely to experience constipation and worsening cognitive function. Together, these results highlight the importance of addressing constipation as we age, by maintaining a balanced, fibre-rich diet, drinking plenty of water, and exercising. Read the AAIC press release:

https://aaic.alz.org/releases_2023/constipation-gut-health-alzheimers-dementia-risk.asp

19 July: New research show that finger-prick blood tests can accurately identify key AD biomarkers

New research findings presented at the Alzheimer's Association International Conference (AAIC), in Amsterdam (Netherlands), show that blood tests may increase the accuracy and accessibility of Alzheimer's disease (AD) diagnosis and monitoring.

This research is timely and important with the recent US Food and Drug Administration (FDA) approvals of AD treatments targeting amyloid-beta where confirmation of amyloid build-up and biomarker monitoring are required to receive treatment.

Hanna Huber from the University of Gothenburg (Sweden) presented a pilot study investigated a new way of detecting key AD biomarkers by dropping a small blood sample onto a blood spot card. The use of blood samples to detect amyloid and other markers of AD has become standard procedure for monitoring patients in clinical trials. However, this presents logistical challenges as it requires strict, time-limited and temperature-dependent protocols.

In this study, researchers designed a method to analyse finger prick tests for AD, which can be performed at home easily without the need for clinician oversight and without a lot of preparation or processing (time, temperature, storage). Blood samples were collected from 77 patients attending a memory clinical in Barcelona using traditional needles and syringes and also from a finger prick, similar to diabetes blood testing. Cerebrospinal fluid samples were also obtained from some patients. The blood samples were transferred onto dry blood spot cards and shipped overnight, without temperature control or cooling, to the University of Gothenburg (Sweden), where they were extracted from the blood spot cards and tested for the presence of AD-related biomarkers. All were detectable in the finger prick samples. In the vein blood spots, the levels of AD-related biomarkers associated strongly with standard blood analysis. The presenting author added that the pilot study shows the potential of remote collection and measurement of AD biomarkers including the future potential for at-home testing by a patient or a family member.

Another study examined for the first time the use of blood-based biomarkers for AD in primary care and compare them to the diagnostic accuracy of primary care physicians. The study recruited 307 middle-aged to elderly patients at 17 primary care centres in Sweden (mean age=76 years old). Primary care exams included cognitive testing and brain scans. Participants also provided a venous blood sample which was analysed to determine concentrations of beta-amyloid and phosphorylated tau.

Findings showed that blood tests were 85% accurate in identifying AD-related changes, significantly better than primary care physicians with around 55% accuracy who did not have access to the test.

"Due to the lack of accurate diagnostic tools, it is currently very difficult for primary care doctors to identify Alzheimer's disease, even among patients with cognitive impairment. This too often leads to diagnostic uncertainty and inappropriate treatment. Blood tests for Alzheimer's disease have great potential for improving diagnostic accuracy and proper treatment of people with Alzheimer's. These tests may become even more important in the near future, as new drugs that slow down the disease in its early stages become more widely available.", said Sebastian Palmqvist, Presenting author from Lund University (Sweden). Read the AAIC press release:

https://aaic.alz.org/releases_2023/finger-prick-blood-test-alzheimers-disease.asp

SCIENCE WATCH

6 July: FDA grants traditional approval for lecanemab for treatment of early Alzheimer's disease

On 6 July 2023, the US Food and Drug Administration (FDA) granted traditional approval to the anti-amyloid drug, lecanemab, for the treatment of early Alzheimer's disease (AD). This approval comes after the unanimous endorsement of its clinical efficacy by an FDA Advisory Committee last month, and represents an important milestone for the Alzheimer's community.

Lecanemab, which is marketed by Eisai and Biogen under the brand name Leqembi, is an antibody that targets plaques of amyloid-beta proteins that accumulate in the brain during the development of AD. The FDA had previously approved lecanemab via its Accelerated Approval pathway based on the positive results of a Phase 2b, randomised and placebo-controlled clinical trial, which recruited 856 participants with mild cognitive impairment (MCI) or mild dementia due to AD.

Traditional approval was based on the results of CLARITY-AD, a Phase 3, confirmatory trial which enrolled 1,795 participants who received either lecanemab (10mg/kg) or a placebo, on a bi-weekly basis, via intravenous infusion. This study met all its primary and secondary endpoints, demonstrating a 27% reduction in clinical decline after 18 months of treatment on the global cognitive and functional scale, CDR-SB. Analysis of Quality-of-Life measures using the EQ-5D-5L and QOL-AD scales showed an average 50% reduction in decline over the 18 months of the CLARITY-AD trial.

The most common adverse events experienced by trial participants receiving lecanemab included amyloid-related imaging abnormalities, also known as ARIA. ARIA most commonly present as temporary swelling in the brain, and may be accompanied by small brain bleeds. While most cases of ARIA are mild or asymptomatic, severe ARIA can cause seizures and other life-threatening symptoms, with a reported incidence of 0.7% in CLARITY-AD. Participants carrying two copies of the ApoE e4 allele had a much higher incidence of ARIA compared to people with only one ApoE e4 copy, or non-carriers. Participants taking blood-thinning, anti-coagulant medication also experienced a larger number of brain bleeds when being treated with lecanemab.

Taking these safety concerns into account, the FDA has included a black box warning of ARIA in the prescribing information for lecanemab. This warning explains that lecanemab can cause ARIA, and states that genetic testing for ApoE e4 should be performed prior to initiation of treatment. The prescribing information explains that lecanemab treatment should be initiated in patients with MCI or mild dementia due to AD and confirmed presence of amyloid beta pathology in the brain. Patient monitoring should include regular MRI brain scans, with three scans during the first 14 weeks of treatment, and caution should be exercised when considering the use of lecanemab in patients on anticoagulant therapy.

In a statement released following the FDA announcement, the US Centers for Medicare and Medicaid Services (CMS) provided further details on health insurance coverage for lecanemab. To be eligible for treatment, patients must have a confirmed diagnosis of MCI or mild dementia due to AD, documented evidence of amyloid beta pathology in the brain, and a prescribing physician who is participating in a registry that collects real-world evidence on patient outcomes. The CMS also stated that this coverage would be extended to similar anti-amyloid drugs that are granted traditional approval by the FDA.

Alzheimer Europe welcomes the traditional approval of lecanemab by the FDA, and the expansion of access to disease-modifying treatments for early AD in the United States. This will give hope to patients and their families, who have long been waiting for therapies that can slow or delay the cognitive and functional decline caused by AD.

European patients cannot yet access this new treatment, as lecanemab is currently undergoing a full evaluation by the European Medicines Agency, following the submission of an application for marketing authorisation approval in January 2023. Decisions by European regulators are not expected before the end of the year, but Alzheimer Europe hopes for a similarly positive outcome at European level.

Read the full FDA announcement, here:

https://www.fda.gov/news-events/press-announcements/fda-converts-novel-alzheimers-disease-treatment-traditional-approval

Find the prescribing information, here:

https://www.leqembi.com/-/media/Files/Leqembi/Prescribing-Information.pdf

10 July: Prof. Steen Frederiksen discusses highlights from European Academy of Neurology Congress with touchNEUROLOGY

In a short interview with touchNEUROLOGY, published online on 10 July 2023, Prof. Kristian Steen Frederiksen of the Danish Dementia Research Center, Copenhagen, Denmark, shares some highlights in the area of Alzheimer's disease and dementia, from the annual European Academy of Neurology (EAN) Congress which took place from 1 to 4 July 2023.

He particulary highlighted the interesting data on prevention and the idea of brain health. He also stressed the focus on sleep in brain disorders and specifically dementia, both as an associated symptom but also as a risk factor. Finally, he noted an interesting poster on the role of aquaporin in the regulation of beta-amyloid.

You can find the interview video, here.

10 July: Observational study finds that altered gut bacteria could be an early sign of Alzheimer's disease

People in the earliest stage of Alzheimer's disease (AD), after brain changes have begun but before cognitive symptoms become apparent, harbour an assortment of bacteria in their intestines that differs from the gut bacteria of healthy people, according to a new study by researchers at Washington University School of Medicine in St. Louis, USA, published in the journal Science Translational Medicine.

During the early stage of AD, which can last two decades or more, affected people accumulate clumps of the proteins amyloid beta and tau in their brains, but do not exhibit signs of neurodegeneration or cognitive decline. Scientists already know that the gut microbiomes of people with symptomatic AD differ from the microbiomes of healthy people of the same age. But, this new study looks specifically at the gut microbiomes of people in the critical pre-symptomatic phase.

To distinguish participants already in the early stage of AD from those who were healthy, the researchers looked for signs of amyloid beta and tau accumulation through brain scans and cerebrospinal fluid. Of the 164 participants, about a third (49) had signs of early AD. An analysis revealed that healthy participants and those with preclinical AD had markedly different gut bacteria, in terms of the species of bacteria present and the biological processes in which those bacteria are involved, despite eating a very similar diet. These differences correlated with amyloid and tau levels, which rise before cognitive symptoms appear, but did not correlate with neurodegeneration, which becomes evident about the time cognitive skills start to decline. These differences could potentially be used to screen for early AD, the researchers said.

A limitation of this study, the researchers noted, is that the gut microbiome can change over time, but stool samples were collected just once. As such, they highlighted a need for future studies that sample the gut microbiome at multiple points in time. The fact that not everyone with preclinical AD will actually develop disease symptoms in their lifetime also stresses the need for further long-term studies, the team noted. They also emphasised that, while these data suggest that the gut microbiome is dysregulated in the early stages of AD, it is unclear whether this finding is a cause or consequence of the disease. If it turns out that the gut is influencing the brain to help drive AD, it might open the door to new treatment strategies and with this in mind, the researchers have launched a five-year follow-up study designed to figure out whether the differences in the gut microbiome are a cause or a result of the brain changes seen in early AD.

Read the study, in Science Translational Medicine: https://doi.org/10.1126/scitranslmed.abo2984

13 July: Healthy cognition levels in the "oldest-old" are not associated with less Alzheimer's pathology but do exhibit less susceptibility to other neurological changes

There is a lack of information about people aged 90 or older who are able to maintain high levels of cognitive function. A recent study published in the Journal of Alzheimer's Disease sought to investigate the brains of people who live to be aged 90 or more and have superior cognitive skills (i.e. good memory and thinking ability).

The researchers, from the University of California, analysed autopsy data from 102 individuals who died at a mean age of 97.6 years old and had normal levels of cognition.

The study demonstrated that there was no significant association between brain changes reflective of Alzheimer's disease (AD) and vascular issues, and superior cognition levels. On the other hand, the "oldest-old" superior cognitive performers were found to be less likely to exhibit brain changes associated with other neurogenerative diseases such as Lewy Body Disease.

The study authors recommend that future research look at the factors that underlie such individuals' ability to resist the changes associated with non-AD neurodegeneration, as this may provide useful insights into how some people can maintain healthy cognition at very advanced ages. Read the full study, here:

Superior Global Cognition in Oldest-Old Is Associated with Resistance to Neurodegenerative Pathologies: Results from The 90+ Study - IOS Press

13 July: Recent review of the literature reveals more details about the effect of music on anxiety and depression in dementia

Researchers at the School of Public Policy and Administration, Xi'an Jiaotong University, Xi'an, China have conducted an in-depth analysis of the impact of music therapy on anxiety and depression in people with dementia. More particularly, the researchers looked at existing studies on the topic: they included 19 articles involving 614 samples. They published their results in the journal Ageing and Mental Health.

For anxiety in people with dementia, it was shown that the music therapy intervention had to last at least 12 weeks for there to be a significant effect. And when the music therapy session was longer, the people with dementia experienced stronger reductions in anxiety.

The analysis also showed that, with regard to their effects on depression or anxiety, less frequent music therapy interventions spread over longer periods of time were preferred over more frequent sessions over a shorter time frame.

The authors concluded that music interventions can effectively reduce depression or anxiety in people with dementia. They specified that, according to their analyses, interventions of 45 minutes or more, at least once a week, were effective. They also recommended that further studies should look at the impact of music therapy on people with severe dementia. Read the full study, here:

https://www.tandfonline.com/doi/full/10.1080/13607863.2023.2214091

13 July: Recent study reveals that a lack of sleep may reduce the benefits of physical activity on cognition

A recently published study in The Lancet Healthy Longevity has investigated how sleep time and physical activity can affect a person's cognitive function over time. The researchers, from University College London, examined the cognitive function and sleep habits of 8,958 people aged 50 years and over in England over a period of 10 years.

They found that those who engaged in more physical activity but slept less (less than 6 hours on average) had faster cognitive decline overall. This means that after 10 years, a more physically active person sleeping less than 6 hours had the same level, on average, as someone who slept more but engaged in less physical activity.

It was found, however, that those who, in general, were more physically active, were linked to better cognitive function compared to those who were less physically active at the very beginning of the study (beginning of the 10-year period). But this changed over the 10-year period, with shorter sleepers experiencing a more rapid cognitive decline.

This more rapid cognitive decline was, however, only applicable to people in their 50s and 60s. On the other hand, older participants, aged 70 and over, still profited from all the benefits of exercise on cognition even if they slept less than 6 hours.

There is already a lot of knowledge about the important beneficial effects of physical activity on cognitive decline. The results highlight that sleep should also be considered when thinking about leveraging the positive impact of physical activity on cognition.

Joint associations of physical activity and sleep duration with cognitive ageing: longitudinal analysis of an English cohort study - The Lancet Healthy Longevity

3 August: Alector provides an update on its INVOKE-2 and INFRONT-3 clinical trials of treatments for early Alzheimer's disease and frontotemporal dementia

On 3 August, the biotechnology company, Alector, reported the financial results from the second quarter of 2023, and provided an update on their ongoing clinical trials for early Alzheimer's disease and frontotemporal dementia.

INVOKE-2 is a randomised, double-blind, placebo-controlled Phase 2 trial evaluating the safety and efficacy of AL002, an antibody drug that activates the TREM2 receptor on immune cells in the brain, prompting them to clear damaging proteins such as amyloid beta. In their press release, Alector announced that they have completed screening for this clinical trial, which includes sites in the US, Canada, UK and Europe. First results from INVOKE-2 are expected towards the end of 2024.

Alector also provided an update on INFRONT-3, a pivotal randomised, double-blind, placebo-controlled Phase 3 clinical trial enrolling participants with or at risk of frontotemporal dementia (FTD) due to heterozygous mutations in the progranulin gene (FTD-*GRN*). INFRONT-3 is evaluating the safety and efficacy of a drug called latozinemab, which they are developing in collaboration with GSK. Latozinemab is a monoclonal antibody which binds to the sortilin receptor, helping to restore levels of progranulin in the blood, theoretically slowing the progression of FTD-*GRN*. In their 3 August press release, the company explained that the European Medicines Agency had provided scientific advice on INFRONT-3, resulting in a more focused enrolment of 90-100 symptomatic individuals. As a result, they anticipate that enrolment will be completed by the end of 2023.

Read the full press release, here:

https://investors.alector.com/news-releases/news-release-details/alector-reports-second-quarter-2023-financial-results-and

MEMBERS' NEWS

1 July: Germany now has 100,000 "Demenz Partners" (Dementia Friends)!

In Germany, the "Initiative Demenz Partner" (Dementia Friends Initiative) is a great success, with 100,000 Dementia Friends now trained by the Deutsche Alzheimer Gesellschaft (DAlzG) – the German Alzheimer society. The Parliamentary State Secretary of the Federal Ministry of Health, Sabine Dittmar personally attended the training and congratulated the DAlzG on their great work.

Within the framework of the National Dementia Strategy, the "Dementia Friends" programme is funded by the Federal Ministry of Health together with the Federal Ministry for Family Affairs, Senior Citizens, Women and Youth

"People with dementia and their relatives often feel isolated because encounters with friends and relatives become fewer or stop altogether. Now 100,000 people in Germany have become dementia partners and every day there are more: you can all contribute to bringing people with dementia into the midst of our society," commented Saskia Weiß, Executive Director of the DAlzG.

www.demenz-partner.de

1 July: Danish Alzheimer's association joins major effort to counter loneliness in Denmark

The national partnership against loneliness, in which the Danish Alzheimer's association (Alzheimerforeningen) is involved, recently presented its strategy and action plan against loneliness in Denmark, at a major event at Christiansborg. The event also saw the unveiling of four initiatives totalling DKK 20.8 million (EUR 2.79 million), which will help to reduce loneliness

and promote local initiatives that benefit people who experience severe loneliness - including people with dementia and their relatives.

Too many people in Denmark feel lonely, and this can have major consequences both for the individual and for society as a whole. Therefore, the parties behind an agreement on the implementation of the reserve for measures in the social, health and labour market area for 2022-2025 (SSA agreement) have allocated DKK 25.5 million (EUR 3.42 million) for a national strategy and action plan against loneliness. In connection with this, a national partnership against loneliness was established, which the Alzheimerforeningen is part of, together with more than 100 actors from civil society, municipalities, companies, etc. All have contributed to the work and the partnership's ambitious and comprehensive strategy, launched at the event in Christiansborg.

Find out more:

https://www.alzheimer.dk/nyheder/2023/alzheimerforeningen-med-i-stor-indsats-mod-ensomhed/

Pictured: Many of the stakeholders in the National Partnership against Loneliness participated in the launch of the strategy at Christiansborg on 21 June 2023

3 July: New online platform brings together information about support services available across the whole of Switzerland

Alzheimer Suisse has created a new online platform, bringing together information about the support services available throughout Switzerland, for the first time on one single site. It lists specialist contacts in the fields of medicine, care and therapy, as well as leisure activities such as dance performances, art exhibitions and guided walks. Using this new platform, www.alzguide.ch, people affected by dementia, their families, and the professionals who advise and support them, will be able to find useful information about services tailored to their needs.

To use the platform, visitors need to enter their postcode and the type of service they are looking for and, within a few clicks, they can find suitable services in their local area. The creation of alzguide.ch was made possible by a generous donor, who herself suffers from a form of dementia, and the support of various foundations. The online platform is constantly being expanded. Individuals and institutions whose offers are not yet listed on alzguide.ch can enter and manage them themselves under www.alzguide.ch/sign-up-info, after verification and confirmation by Alzheimer Switzerland.

8 July: Swedish Dementia Association and Alzheimer's Foundation organise first summer camp for families affected by dementia

This summer, the Swedish Dementia Association (Demensförbundet) was finally able to provide support in various forms for entire families affected by Alzheimer's disease and other forms of dementia. This was the first camp of its kind for families in Sweden, and it was a success. It all started with the fact that the Swedish Dementia Association and Alzheimer's Foundation saw the importance of bringing together the entire family and saw this as very significant, as there are currently no meeting places for affected families in Sweden today. They therefore decided to take action and to focus on supporting whole families.

With this collaboration, Demensförbundet wanted to enable entire families to break away from their everyday lives and meet other affected individuals, share experiences, provide support to each other, and gain knowledge and information. The camp took place during a weekend in July in the south part of Sweden, by the sea.

“It was delightful and important to be able to offer a wide range of activities for different ages and needs” said Demensförbundet, of the programme for the camp, which included activities such as lectures and discussion groups, creative workshops, painting, yoga and massage, stand-up paddle boarding, and much more.

13 families from different parts of Sweden participated. The opportunity for them to get away from their hometowns and meet others in a peaceful and pleasant environment, with a programme tailored to their needs was greatly appreciated.

“Without our fantastic leaders, this would not have been possible - they have all shown strong commitment and attentiveness to the diverse needs of the participants. With their extensive experience and professionalism, each of them contributed in a very nice way to create this successful family camp”, noted Demensförbundet.

Now, the organisations involved hope to arrange more meeting places for families in the future, as a joint project. They believe

they have good conditions to do so, as the organisations complement each other, and "it is of utmost importance that we come together to give voice and comfort to the families affected by Alzheimer's disease and other forms of dementia", they conclude.

31 July: Alzheimer Hellas participates in creating new mobile game for development of cognitive skills and learning strategies for adults with Intellectual Disabilities "Game4CoSkills"

Alzheimer Hellas is participating in the development of an innovative mobile game. Game4CoSkills which is a European Erasmus+ programme. Six countries participate in this project: France (Interactive 4D), Austria (Austrian Association of Inclusive Society-AIS), Italy (Euro-Net), Greece (Alzheimer Hellas), Cyprus (Synthesis Center for Research and Education) and Turkey (Avrasya Yenilikçi Toplum Derneği) and the duration of the project is 24 months.

The aim of Game4CoSkills is to develop a new mobile game which improves eight cognitive skills of adults with Intellectual Disabilities (ID). Result 1 and Result 2 have been completed.

In Result 1, a study was conducted on the cognitive skills of adults with ID such as mild cognitive impairment (MCI), dementia, Alzheimer's disease (AD), Autism and Down syndrome. 329 health professionals provided details of the profiles of people with ID.

In Result 1, it was also shown that people with ID have, often or sometimes, difficulties in recognising the colours in a picture. There were also significant difficulties with the use of memory skills, as most of the adults with ID showed deficits in remembering names and where they placed a personal item. They also showed difficulties with calculation, with some of them having completely lost this ability. The skills of logical thinking, accuracy, dexterity, multitasking, and attention to detail were also found to have declined.

Finally, it was reported that this population had difficulties in playing mobile games, but that most could use a mobile phone, with or without difficulty.

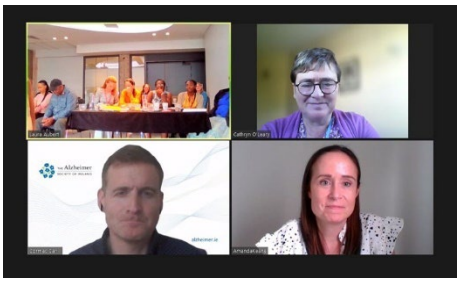
In Result 2, the mobile game was developed based on Result 1 and the pilot study has now been implemented, with people with ID and health professionals playing the game in all partner countries.

The game has been uploaded on Google Play https://play.google.com/store/apps/details?id=com.Interactive4D.g4cs and can be found also as a PC version: https://game4co.eu. Available languages are English, French, Italian, Greek, German and Turkish.

In July, the partners visited Thessaloniki, where Alzheimer Hellas scheduled a meeting to discuss the progress of the project. The pilot study in Thessaloniki will take place during the month of September.

Find out more about Game4CoSkills: http://game4coskills.eu/

18 August: The Alzheimer Society of Ireland team presents on "Working with Volunteers" at the Alzheimer's Disease International Alzheimer University for Emerging Associations



Head of Advocacy, Research & Public Affairs at The Alzheimer Society of Ireland (ASI), Cormac Cahill MPRII, National Community Engagement Manager Cathryn O'Leary, and Information & Helpline Officer Amanda Keane, were delighted to present on "Working with Volunteers" at the Alzheimer's Disease International (ADI) Alzheimer University for Emerging Associations, including Botswana, Serbia, and Grenada. The event took place from 15-18 August 2023.

It was a thoroughly enjoyable session and the team covered many interesting topics such as volunteer roles, the recruitment of volunteers, and two inspiring case studies, Creating a Dementia-Inclusive Community and The Alzheimer Society of Ireland Alzheimer National Helpline.

Volunteers have been the lifeblood and backbone of The ASI since the charity was founded in 1982, and its expansion and development simply would not have been possible without their volunteers' continuing commitment and involvement.

23 August: Spominčica – Alzheimer Slovenia participates in new Erasmus+ project "FLOWER" which aims to reduce the risk of dementia through nature-related activities and conservation

Spominčica – Alzheimer Slovenia is participating in the new ERASMUS+ project FLOWER, which focuses on the importance of nature in improving quality of life for older/frail people and hoping to delay or slow down the progression of dementia, in this population. The Erasmus+ project brings together the lead partner Stichting Gouden Dagen from the Netherlands and partners from Spain, Italy and Slovenia.

There is strong evidence that being connected to nature has significant benefits for older people, including increased vitality, improved mental health and cognitive abilities, more social interactions and greater life satisfaction. However, many older people, including those with physical disabilities or dementia, spend most of their time indoors, which limits their connection to nature. FLOWER aims to encourage them to spend more time in nature to improve their wellbeing, health and social inclusion. The project focuses on strengthening the

nature-related competences of older people, their families and friends, and provides them with the opportunity to acquire knowledge, skills and activities related to nature.

The project will provide guided activities and workshops in nature for older/frail individuals and their informal caregivers and will produce a set of online learning resources with video, audio and other tools (workbooks, cards, games, etc.) specifically designed for this population; facts about the benefits for them of being outside in nature, with tips and tricks to enjoy nature in an accessible way; creative and meaningful activities that can be done together in nature, stimulating the senses and fostering social cohesion between generations.

In the last month, Spominčica and the other project partners have completed a state-of-the-art analysis and gathered best practices on nature-related activities for older/frail people and their carers. These practices aim to foster increased social inclusion, enhanced well-being, and improved health within the community. In alignment with the project's commitment to environmental care, the partners have thoroughly examined and documented the best practices on teaching "green skills" and other nature-related competences.

Going full steam ahead, they are setting up innovative co-design and co-creation methods to ensure that their activities resources are tailored to the specific needs and wishes of older/frail people and their informal caregivers.

https://flowerproject.eu

26 August: The Alzheimer Society of Ireland launches Pre-Budget Submission 2024 #DementiaCantWait

Earlier in the summer, The Alzheimer Society of Ireland (ASI) made a Pre-Budget Submission (PBS) #DementiaCantWait to government for funding for the year ahead. With a strong PBS grounded in the lived experience of dementia, the event saw incredible cross-party support, with over 60 elected representatives in attendance and a visit from The Minister of State for Mental Health and Older People, Mary Butler. The event also garnered national media coverage.

The ASI called for funding for Dementia Specific Day Services, Therapeutic Support and Education for Family Carers; Dementia Home Care, Dementia Nurse Specialists, Memory Clinics and Research as well as investment to secure Pay Parity for workers in The ASI and Social Protection for Dementia Carers.

The PBS took place following months of robust consultation with stakeholders, including people with dementia and those who support them, The ASI team including Operations, Dementia Advisors, the Senior Management Team, the Irish Dementia Working Group and the Dementia Carers Campaign Network.

Find out more about The Alzheimer Society of Ireland Pre-Budget Submission, here:

https://alzheimer.ie/creating-change/political-campaigns/dementia-cant-wait-dementia-supports-to-empower-lives/

26 August: The Alzheimer Society of Ireland and Irish Dementia Working Group appear in Irish media responding to positive news about donanemab clinical trials

The Alzheimer Society of Ireland (ASI)'s response to the announcement of results around the TRAILBLAZER-ALZ2 Phase III clinical trial of the Alzheimer's drug donanemab, garnered significant national Irish media coverage.

Interviews with The ASI Research and Policy Manager Dr Laura O'Philbin widely featured in print and broadcast media. Dr Laura O'Philbin was also interviewed by national broadcaster RTÉ, along with Board of Directors member and Vice-Chair of the Irish Dementia Working Group Helen Rochford-Brennan (pictured, right).

Results of the donanemab trial were presented by American pharmaceutical company Eli Lilly representatives at the Alzheimer's Association International Conference in Amsterdam, in July 2023.

29 August: Digital Neuro Signature study is carried out in Greece by the Panhellenic Federation of Alzheimer's Disease and Related Disorders

Since October 2022, Alzheimer Hellas in collaboration with Altoida and Eisai carries out the DNS (Digital Neuro Signature) study, which aims at the early detection of Alzheimer's disease (AD). Until now, detection methods have been cross-sectional and limited, with large cognitive tests that are done at a specific time and repeated after intervals.

A plethora of external factors, such as motivation, attention, mood, etc., make the conducting of reliable diagnosis and the investigation for treatment efficacy difficult. In order to meet the challenge of these complications, the study using longitudinal testing, through a special application, manages to continuously elicit frequent, smaller pieces of cognitive information, for extended time periods.

Through digital tools such as PCs, smartphones, tablets and smartwatches, the study monitors digital biomarkers of biological or behavioural data. This data can be either active measurements, e.g. reaction time, or passive, like tremor or hesitation. Anyone who is at least 50 years old and has a smartphone device is eligible to participate in the study by visiting the Nursing Home of Alzheimer Hellas "Panagia Glykofiloussa".

To achieve a reliable diagnosis, participants are asked to follow a series of tests and assessments, carried out free of charge. Initially, cerebrospinal fluid is taken through lumbar puncture by an experienced neurologist, blood and saliva samples are taken and a neurological assessment is performed. In addition, a neuropsychological assessment is carried out by experienced psychologists, with information collected from participants and caregivers. Measurements related to motor and cognitive activities are carried out with the Altoida application via a tablet.

At the end, participants receive a smartwatch connected to their mobile device and, with guidance from the research staff, instructions are given for its use. Each participant is required to wear the smartwatch and synchronise the data with the smartphone application. All data is collected remotely for the assessment of participants' cognitive and motor activities.

Finally, MRI, FDG and Amyloid PET scans are prescribed for chosen participants. The participant is invited to visit the centre, for examinations and reassessments, at one-year intervals after the initial visit and for a total of five years. The physician in charge reports the results and the diagnosis. Participants with positive biomarkers for AD have direct access to all medicines approved by the European Medicines Agency. The early detection of AD leads to early initiation of treatment, an opportunity to participate in clinical trials and prepare for the future.

29 August: Alzheimer Hellas and MOMus Thessaloniki Museum of Photography collaborate on an innovative new initiative for people with dementia

For those of us who are not able to or not brave enough yet to dare create a work of art, a visit to a museum or getting to know works of art through books can also be therapeutic experiences. Even merely looking at works of art can refresh one's spirit and induce relaxation. With this in mind, earlier this year, an interesting and innovative programme was co-organised by Alzheimer Hellas and MOMus Thessaloniki Museum of Photography.

Visiting the Museum is an opportunity to approach a photographer's story, along with the beneficiaries of "Agia Eleni" Day Centre, and see how the camera becomes a means to approach something new and different and see a photograph become a work of art. Photography is not only an art but also a science, because it involves recording electromagnetic radiation. It has its own language, code, premises, interactions with external factors, expressive tools, technical means, as well as its own potential and limitations. Besides, it can also be a means for one's personal creative expression. This aspect can transform photography into a psychotherapeutic and self-awareness/knowledge tool capable of helping us to connect with our feelings. It can move us, cause anger, incite action, bring about change, give us pleasure, encourage us, animate us, give us food for thought related to our inner state and life.

John Zeisel, the founder of "Artists for Alzheimer's" helped the staff at the Museum of Modern Art in New York to create a programme for people with dementia. Mr Zeisel supports that viewing a work of art is therapeutic for people with dementia because some inert brain parts that are still functional are engaged. Additionally, their involvement in the process can help boost self-esteem. The experience enhances a person's sense of dignity and help them "reclaim their personality", says John Zeisel.

Consequently, the museum visits organized by Alzheimer Hellas and MOMus provide an opportunity for an artist's photographs to become a means for creating psychotherapeutic interventions to help beneficiaries approach the art of photography and express themselves, remember, narrate their personal stories and relate to themselves and others.

DEMENTIA IN SOCIETY

5 July: Singer-songwriter Ben Walker speaks to what matters most in our closest relationships, in his song "I Won't Forget", written for his mother who has Alzheimer's disease

Ben Walker is a singer-songwriter based in Sydney, Australia. Last February, his mother, who lives in the United Kingdom, was diagnosed with Alzheimer's disease. After many months of working through this news and understanding what the diagnosis really meant, he turned to fellow musicians Allan Caswell, Beth Lucas and Stephen Dobson and co-wrote a song called "I Won't Forget". The lyrics explore what matters most in our closest relationships. The song was released recently and has enjoyed considerable success, going to Number One on the Australian Country Radio chart as well as reaching the Top Ten on Australian Community radio. It has also been featured on the Australian Alzheimer Research Association's website: https://alzheimers.com.au/a-song-to-say-i-love-you/

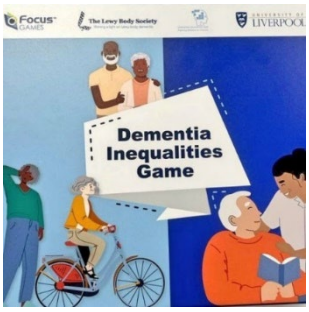
There is a music video available online: https://youtu.be/xBSnWqyie48

And the song is available on Soundcloud:

https://soundcloud.com/benwalkermusic/i-wont-forget/s-yITi917WkJX?si=604fbfcee0c7452c9f1b6002a1089501&utm_source=clipboard&utm_medium=text&utm_campaign=social_sharing

NEW PUBLICATIONS AND RESOURCES

30 August: New "Dementia Inequalities Game" aims to improve awareness and understanding of dementia and associated inequalities



Dr Clarissa Giebel, Senior Research Fellow at the University of Liverpool and NIHR ARC (National Institute for Health and Care Research Applied Research Collaborations) North West Coast, and her colleagues, have designed a new game, the "Dementia Inequalities Game". It was announced in July 2023 and was made available for attendees to test out, at the Alzheimer's Association International Conference (AAIC), which took place from 16 to 20 July in Amsterdam.

The game was co-designed together with people with dementia, carers, care providers and representatives of the voluntary sector, also known as the third sector. It aims to improve awareness and understanding of dementia and associated inequalities, whilst discussing the topic with fellow game players. It is designed for people with dementia, carers, health and social care professionals, as well as the general public and can be used as a training tool for social care professionals, medical students, or allied health professionals.

Shortly, the final game will be available on the Lewy Body Society webpage, co-funded by LBS and SURF Liverpool: https://www.lewybody.org/shop/

EDUCATION

30 August: Fondation Médéric Alzheimer schedules special symposium on psychosocial interventions at this year's Alzheimer Europe Conference and invites input to survey on same topic

Psychosocial interventions, also called non-drug or non-pharmacological interventions, are essential to maintaining and/or improving cognitive, psychological, social and physical functioning and quality-of-life of people with dementia.

Since 2011, the Fondation Médéric Alzheimer has been conducting surveys among French facilities for people with dementia and family caregivers, in order to provide an overview of the implementation of psychosocial interventions, among other things.

The Fondation will organise its first symposium at the 33rd Alzheimer Europe Conference, with the presence of INTERDEM members, on Tuesday 17 October 2023 from 5.30pm to 6.30pm. The aim will be to better understand how psychosocial interventions are implemented in Europe and to identify similarities and differences. In order to prepare this symposium, the Fondation Médéric Alzheimer has launched a flash survey on psychosocial interventions in Europe. During the symposium, participants will be invited to answer the survey questions live and the results will be presented and compared with those of the survey.

If you are a professional, a person with dementia or a family caregiver, and you are concerned by psychosocial interventions, take a few minutes to complete this flash survey before 15 September 2023: https://app.keysurvey.fr/f/41671371/109a/

For more information or any questions, please contact Jean-Bernard Mabire, Project Manager at the Fondation Médéric Alzheimer: mabire@med-alz.org

JOB OPPORTUNITIES

4 September: We are recruiting for two new full-time permanent positions - a Public Involvement Officer and a Project Officer

Alzheimer Europe is looking to fill two new full-time Luxembourg-based positions, on a permanent basis:

Public Involvement Officer

As the Public Involvement Officer, you will:

- Become an active member of the organisation's public involvement team and support all Public Involvement activities of Alzheimer Europe
- Collaborate with and support the European Working Group of People with Dementia and the European Dementia Carers Working Group and their contributions to AE's work and involvement in research projects
- Support the development of the Public Involvement Pool and of new consultation methods to include the views of people at risk of developing dementia
- Help with the writing of dementia-inclusive publications
- Contribute to scientific publications on Public Involvement in European dementia research
- Help in the dissemination of EU-funded research projects
- Support the communication of medical and research developments to the wider dementia community and the general public via the organisation's newsletter, magazine and website

You should have the following experience and qualities:

- Good people skills and the ability to work and communicate with people with dementia and their carers

- Completed university education in a scientific field (such as dementia studies, psychology, sociology, anthropology, philosophy or similar)
- Experience in a similar position (background in Public Involvement would be considered an advantage)
- A good understanding of dementia research and the contributions to research of people with dementia and their carers
- A perfect knowledge of English (knowledge of other European languages would be a plus)
- Excellent writing and communication skills, including communicating scientific concepts in easy-to-understand language
- Experience of social media
- Proficiency in Microsoft Office applications
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad and present at project meetings, scientific conferences and other networking opportunities.

Project Officer

As the Project Officer, you will:

- Contribute to EU-funded projects in the fields of artificial intelligence, brain health, data sharing and dementia risk prediction by supporting the following tasks
- Develop communication strategies and stakeholder engagement plans
- Conduct stakeholder mapping and stakeholder engagement activities
- Develop and deliver communication activities, creating written content, visuals and campaigns
- Develop policy positions and recommendations relating to dementia research and the implementation of research findings.
- Collaborate with the Public Involvement team to identify the views of people with dementia, carers and people with mild cognitive impairment on these topics
- Support the communication of medical and research developments to the wider dementia community and the general public via the organisation's newsletter, magazine and website

You should have the following experience and qualities:

- Completed university education in a scientific or public health field
- Experience in a similar position (background in EU projects or working for a European NGO would be considered an advantage)
- A good understanding of public health and/or dementia research
- A perfect knowledge of English (knowledge of other European languages would be a plus)
- Excellent writing and communication skills, including communicating scientific concepts in easy-to-understand language
- Experience of social media
- Proficiency in Microsoft Office applications
- A keen sense of responsibility, initiative and ability to work in a small team
- Willingness to travel abroad and present at project meetings, scientific conferences and other networking opportunities.

To apply for either of these two positions:

Please send your CV, together with a cover letter (both documents in English), **by 30 September 2023**, to: Alzheimer Europe, 14, rue Dicks, L-1417 Luxembourg or via E-mail to info@alzheimer-europe.org

Please note that, to apply, you must be an EU citizen or have an EU work permit.

Contact Alzheimer Europe:
Alzheimer Europe: 14, rue Dicks (L-1417), Luxembourg; info@alzheimer-europe.org; www.alzheimer-europe.org

AE CALENDAR 2023

Date	Meeting	AE representative
1 September	EDCWG and carers from the EWGPWD	Ana and Dianne
4 September	Interdem taskforce Inequalities in Dementia Care	Ana
6 September	EFPIA Patient Think Tank	Owen
7 September	Meeting with Adam Smith, Programme Director, Dementia Researcher, University College London	Ana, Dianne and Kate
12 September	Accessible Communications for all – introduction training for members by the International Association of Accessibility Professionals (online)	Kate
12 September	Meeting with Bristol Myers Squibb	Jean
13 September	Board of Alzheimer Europe Foundation	AEF Board
14 September	EWGPWD meeting	Dianne, Ana, Daphné and Soraya
15 September	LETHE review period II	Ana
19 September	Meeting of Project Alzheimer's Value Europe (PAVE)	Jean
21 September	EU4Health Civil Society Alliance	Owen
21 September	eBRAIN-Health PPAG Consultation	Daphné
25 September	Alzheimer Europe Board	AE Board
26 September	Alzheimer Europe Company Round Table	AE sponsors and Board
27 September	AAIC Participant Inclusion Project Debrief	Daphné and Soraya
28 September	SciCom Luxembourg (Luxembourg, Luxembourg)	Chris
29 September	Lilly Stakeholder Meeting (Paris, France)	Jean
29 September	DataSavesLives Core Group meeting	Ange

CONFERENCES 2023

Date	Meeting	Place
15-19 October	WCN 2023 - The XXVI World Congress of Neurology, https://wcn-neurology.com/	Montreal, Canada
16-18 October	33rd Alzheimer Europe Conference, "New opportunities in dementia care, policy and research", www.alzheimer-europe.org/conference Helsinki, Finland	Helsinki, Finland
25 October	Liverpool Dementia & Ageing Research Forum, https://www.alzheimer-europe.org/node/237018	Liverpool, UK

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33rd Alzheimer Europe Conference

New opportunities in dementia care, policy and research

Helsinki, Finland

16 - 18 October 2023 #33AEC

www.alzheimer-europe.org/conferences