

ALZHEIMER EUROPE NEWSLETTER

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WELCOME



I trust that, despite the current circumstances, you have all enjoyed the summer break. As every year, this edition of our newsletter covers both July and August.

Firstly I would like to extend our deepest sympathies to the family and friends of Paul Diederich, founding member, longtime president and honorary president of Association Luxembourg Alzheimer (ALA). He will be greatly missed and the Board and staff at ALA have said they will dedicate their continuing work to his memory.

The past weeks, we have been busy lobbying at the European level. We wrote to the EU Vice-President for Democracy and Demography and to the EU Health Commissioner, asking that dementia be prioritised within EU policies, including in the EU4Health programme. We received a rather disappointing response – you can read more in the “EU developments” section. We also published a position paper, together with our members, calling for urgent action on the impact of COVID-19 on dementia research. We set out a number of recommendations aimed at research funders and research institutions. Find out more in the “Alzheimer Europe” section of this newsletter. Also on the topic of COVID-19, Germany took over the Presidency of the Council of the European Union as of July and among the priorities for its six-month tenure, is putting an end to the pandemic. Alzheimer Europe is delighted to have been involved as a co-author on two different

papers published during July: A JPND paper on “Measuring the well-being of people with dementia: a conceptual scoping review”; and a European Academy of Neurology guideline on medical management issues in dementia. It is always a pleasure and an honour to be involved in such collaborations.

There has been some big news on the science front, recently, with Biogen filing for an FDA license for aducanumab. The FDA has granted the application priority review, meaning a response will be given by 7 March 2021. There was also a lot of media attention around the publication of the findings of the Lancet Commission on dementia prevention, intervention and care, which identified 12 modifiable risk factors accounting for 40% of dementias.

A number of other noteworthy scientific developments were announced during the online Alzheimer’s Association International Conference (AAIC), which I attended together with some of my Alzheimer Europe colleagues. We report on some of the biggest stories emerging from the conference, in the “AAIC watch” section on pages 20-22.

Regarding our own conference, we are all looking forward to the 30th Alzheimer Europe Conference (#30AEC), our first ever virtual annual conference. We have selected the online platform for this event and registration is now open, so please take advantage of the early bird registration fees, available until 15 September.

We hope to see you there, in October!

Jean Georges
Executive Director

COVID-19 SITUATION

1 July: Fundamental Rights Agency publishes bulletin on COVID-19 and older people



The European Union's Fundamental Rights Agency (FRA) has published its third bulletin on the

implications of the COVID-19 pandemic in the context of rights, examining the actions taken by EU Member States.

This edition of the bulletin specifically addresses a number of issues which have impacted upon the rights of older people, including:

- **Right to life** – the death rate among older people has been much higher than among other age groups – particularly in institutional settings
- **Access to healthcare** – as national healthcare systems have come under pressure, doctors were forced to decide who to treat, with some EU countries using patient age as a criterion for prioritising treatment
- **Lack of testing** – testing of care home residents and staff has been lacking
- **Stricter restrictions** – many EU countries had stricter rules for older people than for the general population
- **Isolation** – lack of social contacts took a toll on the physical and mental well-being of older people
- **Healthcare delays** – many countries suspended non-urgent treatments, which affected many older people who have existing health conditions.

In addition, the bulletin identifies that EU countries need better data to understand how the pandemic has affected older people to help governments make evidence-based decisions for the future.

Furthermore, the FRA recommends that as societies reopen, governments should specifically address the needs of older people, as the move towards new societal norms will likely be slower and more difficult for them. You can access the full report at:

<https://fra.europa.eu/en/news/2020/respect-older-peoples-rights-when-exiting-covid-19-pandemic>

3 July: ECDC issues guidance on the provision of support for medically and socially vulnerable populations during the COVID-19 pandemic



On 3 July, the European Centre for Disease Prevention and Control (ECDC) published a technical report providing guidance on the provision of support for medically and socially vulnerable populations during the COVID-19

pandemic. Medically vulnerable groups are defined as those

who are at higher risk of severe complications from COVID-19, including older adults and people with underlying health conditions such as hypertension and diabetes, while the socially vulnerable category includes groups such as people with chronic physical, intellectual or sensory impairments; ethnic minorities; and homeless people.

Based on an exploratory literature review and a public survey, the ECDC report identifies specific challenges faced by the groups listed above, and describes the ways in which organisations have addressed these challenges. In particular, the report highlights issues with access to healthcare services, crowded living conditions, poor health literacy, stigmatization, discrimination and lack of inclusion. As a result, medically and socially vulnerable populations are at greater risk of mortality due to COVID-19; for example, people with intellectual and developmental disabilities have double the case fatality rate, while several COVID-19 outbreaks have been reported in shelters for homeless people. Organisations that support medically and socially vulnerable groups have experienced unprecedented levels of demand for their services, and have made substantial efforts to adapt their systems to meet this demand whilst respecting the physical distancing measures. Indeed, the ECDC report emphasizes that civil society and charitable organisations have made remarkable efforts to maintain their provision of services during the pandemic, despite the financial and logistical challenges.

To address these challenges, the ECDC report suggests good practices for action during the COVID-19 pandemic. These include universal and equitable inclusion in national public health systems, by prioritizing health over immigration or social status; counteracting stigma by spreading factual messages around COVID-19 in an accessible way; using online consultations with healthcare providers to ensure continuity of care; and promoting meaningful social connections with others despite physical distancing. The report also highlights the need for greater financial and political support from national and regional authorities, to ensure the rights of vulnerable populations are upheld.

<https://www.ecdc.europa.eu/en/publications-data/guidance-medically-and-socially-vulnerable-populations-covid-19>

7 July: World Health Organisation publishes iSupport Lite resources for caregivers of people with dementia



On 7 July, the World Health Organisation (WHO) announced the publication of a series of iSupport Lite resources aimed at supporting caregivers of people with dementia.

These resources were created in response to the closure of many community-based services for people with dementia and their caregivers due to COVID-19, and aim to provide a series of practical support messages to help reduce caregiver stress.

The iSupport Lite resources are easy read posters that are based on iSupport, the WHO skills and training programme for caregivers of people with dementia. The six posters provide tips on reaching out to others for support, providing everyday care for people with dementia, and communicating information to people with dementia, among other topics.

iSupport Lite resources:

<https://www.who.int/teams/mental-health-and-substance-use/brain-health/integrated-care-support/isupport-lite>

iSupport online training programme and manual:

<https://www.who.int/publications/i/item/isupport-for-dementia>

7 July: European NGOs publish open letter on COVID-19 and long-term care facilities

The European Public Service Union, AGE Platform and the European Disability Forum have published an open letter, signed by 88 MEPs, demanding that the European Parliament investigate the effects of COVID-19 on long-term care facilities. The letter highlights that whilst the data collected in different countries are often partial and fragmented, it is evident that most COVID-19 infections and deaths in Europe have occurred in nursing and care homes, as well as residential services for older people and person with disabilities.

In addition, the letter acknowledges that whilst the figures reflect the greater susceptibility and vulnerability of the residents of long-term care facilities, there are problems in the emergency management which must be clarified, such as residents and workers often being exposed to great risks without appropriate safeguards. You can access the open letter at:

<https://www.epsu.org/article/meps-commit-pressure-european-parliament-investigate-impact-covid-19-long-term-facilities>

28 July: The Alzheimer Society of Ireland highlights results from its research on the experiences of people with dementia and carers during COVID-19 pandemic

On 7 July 2020, The Alzheimer Society of Ireland (ASI) published further research on the experiences of people living with dementia and family carers during the COVID-19 Pandemic. This follows on from a [previous report](#) on this subject published in April.

126 informal carers and 15 people living with dementia took part in a survey online or over the phone. It was found that:

- COVID-19 is having a serious negative impact on people living with dementia and family carers mainly due to closure of dementia-specific services and activities.
- The report highlights that 86% of carers are concerned about a decline in the health of their loved one while 58% of people with dementia report feeling “lonely”, “isolated”, “trapped” and “confined”.

- Family carers who are dealing with grief, loss and a tremendous workload are often facing this crisis alone as they feel unable to reach out to other family members at this time. 77% of carers have said their caring workload has increased since COVID-19.
- This situation is being made all the more unbearable as there was a substantial delay in releasing guidelines or a roadmap for reopening vital services such as day care, Alzheimer Cafes and support groups for people with dementia.
- The report has revealed worrying long-term implications of the lockdown with 75% of respondents with dementia and 61% of family carers feeling concerned about their mental health.

On 28 July, The ASI highlighted these results, listened to experiences of people with dementia and family carers first-hand, and called for action in a public webinar. Over 180 people tuned it and The ASI was delighted that guidelines were released by the Irish Government on that same day.

You can read the research report or a plain language summary by visiting:

<https://alzheimer.ie/creating-change/research/>



Pictured: Research Webinar (l-r) - The ASI's Laura O'Philbin, Tina Leonard, CEO Pat McLoughlin, Carer Denise Monahan, Bernadette Rock, Cormac Cahill, Advocate Jacinta Dixon and Clodagh Whelan

29 July: US Alzheimer's Association announces the launch of an international brain study on the long-term impact of COVID-19

In response to the global COVID-19 pandemic, the Alzheimer's Association has announced the launch of a new research study to track and understand the long-term impact of SARS-CoV-2 (the virus that causes COVID-19) on the brain.

Bringing together scientists from over 25 countries, and supported by technical guidance from the World Health Organisation, the study will evaluate cognition, behaviour and brain function in participants from clinical registries, existing cohorts, and upon discharge from hospital. In total, the research consortium aims to recruit 20-40,000 participants for long-term follow-up. To ensure that datasets from different sources can be seamlessly integrated, data collection processes will be harmonised across cohorts. The research study will collect cognitive assessment, neuroimaging, biomarker and clinical data.

This study represents a unique opportunity to identify the risk factors for adverse outcomes, evaluate the influence of cultural factors such as stigma, and study the impact of genetic and environmental risk factors on long-term outcomes following COVID-19 infection.

https://www.alz.org/aaic/releases_2020/covid-19-cognition-media-panel.asp

30 July: Lockdown isolation causes shocking levels of decline for people with dementia, Alzheimer’s Society UK investigation finds



Lockdown isolation is causing “shocking levels of decline for people with dementia, who are rapidly losing memory, speech, and ability to dress and feed themselves” concludes an Alzheimer’s Society investigation carried out during the COVID-19 pandemic.

The results of the investigation, which involved almost 2,000 respondents affected by dementia, were published on 30 July 2020. They show that, since the beginning of lockdown, more than 4 in 5 (82%) report a deterioration in their own symptoms/ the symptoms of the person they are caring for.

Of those who had seen a decline, around half reported increased memory loss (50%) and difficulty concentrating (48%). More than 1 in 4 (27%) said reading and writing had become more difficult, and 1 in 3 reported the same for speaking and understanding speech (33%). “Worryingly, more than a quarter had seen a loss in the ability to do daily tasks, like cooking or dressing”, writes Alzheimer’s Society.

“The coronavirus pandemic has hit people with dementia the hardest, both in terms of deaths from the virus itself, and from a huge increase in “unexplained” non-virus-related deaths, totalling over 13,000 additional deaths between March and June. The knock-on effect of lockdown is interruptions and suspensions to health and social care services, upended

routines, care home visitor restrictions and a prolonged period of social isolation for people with dementia”.

The findings confirm what the charity has heard since March through its Alzheimer’s Society Dementia Connect support line, with symptom deterioration second only to mental health impact as the most common reason for calling.

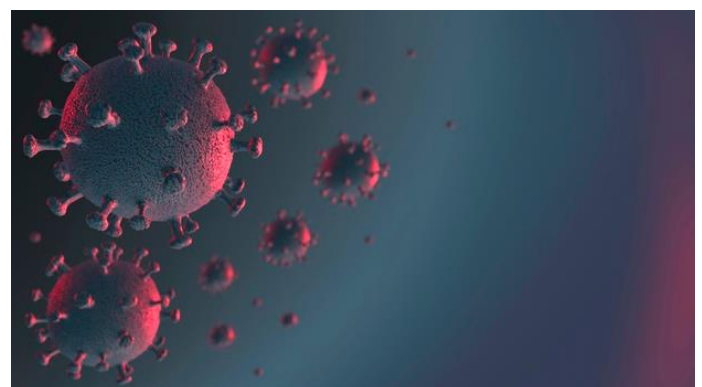
With almost a third (29%) of people with dementia also reporting that the pandemic has had a negative effect on other aspects of their physical health or underlying conditions, the charity fears a further tragic loss of life, especially in the event of a second coronavirus wave over winter.

Alzheimer’s Society has joined forces with a coalition of the leading UK dementia charities, One Dementia Voice, to demand designated family carers are prioritised for safe, regular testing, just like Key Workers, and are seen as equal partners in care, so they can visit loved ones with dementia in care homes. The coalition is very concerned that the Government has handed over responsibility for allowing visits to overstretched local decision-makers, raising the possibility of a “postcode lottery” in access.

“The Government must ensure that it’s understood that family carers are an integral part of the care system and when removed, the essential care and wellbeing of the individual suffers.” You can read the full report on this investigation, here:

<https://bit.ly/3hOXOYI>

3 August: Older adults are experiencing increased marginalisation due to the COVID-19 pandemic



On 3 August, Dr Migita D’cruz and Dr Debanjan Banerjee of the National Institute of Mental Health and Neurosciences in Bangalore published an advocacy review in Psychiatry Research, describing how social and health factors have particularly marginalised older adults during the COVID-19 pandemic.

Sponsors of the month

Alzheimer Europe would like to express its gratitude to four new sponsors for its 2020 activities.

Read more about sponsorship opportunities here:

<http://bit.ly/sponsorAE>




In their review, the authors summarise the direct and indirect risks to older adults during the COVID-19 pandemic, many of which are unique to this age group. In terms of direct risks, the most well-studied is the increased risk of COVID-19 morbidity and mortality in older adults. Less well-studied are the increased risks of adverse drug reactions when treated with COVID-19 drugs such as interferon- or plasma therapy. Indirect risks include loneliness and social isolation, elder abuse and, crucially, ageism: the authors draw attention to media reports that normalise ageist beliefs, calling on older adults to remain at home and not burden health systems.

As a result of these direct and indirect risks, the authors argue that older adults are experiencing increased marginalisation and societal exclusion, amplified by the utilitarian approach to physical distancing employed by many governments. These approaches have led to isolation of older adults in the community, removing them from their usual support structures and compounding pre-existing inequalities.

Highlighting the Alzheimer Europe position statement on triage decisions during the COVID-19 pandemic, Drs D'cruz and Banerjee call for older adults to be prioritised for access to protective equipment and testing, with greater investment in public health strategies that ensure continuity of care despite lockdown measures. Of note, the authors draw attention to recent reports indicating that some people with dementia have experienced worsening symptoms during COVID-19 lockdown, recommending home-based physical and cognitive activities that could have therapeutic benefit for these groups.

They emphasise that older adults should be included as active stakeholders in healthcare, embedding the principles of Healthy Ageing in the development of public health strategies to address the COVID-19 pandemic.

<https://www.sciencedirect.com/science/article/pii/S0165178120324811>

24 August: Larissa chapter of Panhellenic Federation of Alzheimer's Disease organises home-based activities for people with dementia during COVID-19 lockdown

Ensuring autonomy and fuelling the cognitive functions of people with dementia is a pivotal requirement during the period of the COVID-19 crisis says Alzheimer's Larissa, a member of the Panhellenic Federation of Alzheimer's Disease and Related Disorders.

President of Alzheimer's Larissa, Eleni Nifli, seeking the empowerment and the activation of a group of



eleven people with dementia, maintained constant personal contact via telephone. She gave various ideas for activities and suggested that everyone choose what they want to do.

Konstantina, the youngest and most active of the group's members, chose to deal with aromatic plants. One morning, she and her husband went to a nearby gardening centre. They bought basil, soil and purple pots. She planted the basil in 5 pots, took great care of them and when they had grown significantly, she took pictures of them. She then sent the photos to the other group members.

Group member, Roula, was inspired and decided to plant peppermint and parsley, while another member, Dina, planted louisa (lemon verbena). Other members of the group preferred to do puzzles.

On 9 June, after the end of the lockdown, Alzheimer's Larissa reopened and the group returned to its previous normal activities. To the surprise and pleasure of the group, Konstantina brought her basil pots with her, with the help of her husband. She said that during the lockdown she not only took care of the basil but also read about the history of the plant and learned that it is considered to be sacred and a symbol of Christian love. She kindly donated the basil pots to the President of Alzheimer's Larissa and to the association's volunteers, as a sign of gratitude for their constant interest and selfless contribution to people with dementia.



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7 and 9 July: Members of the European Working Group of People with Dementia meet online

On the 7 and 9 of July members of the European Working Group of People with Dementia (EWGPWD) met online in small groups and discussed the topic of inclusive meetings and venues for people with dementia.

Members referred to their experiences of what has facilitated in the past their participation in meetings and events and also, issues which made it challenging. For these discussions, three sessions were organised, each of which were attended by 3-4 members and their supporters. The Chair and vice-Chair of the group attended all the break-out sessions.

During July and August, members have also actively discussed, by email, their plans for the virtual symposium of the EWGPWD at the 30th Alzheimer Europe Conference #30AEC.

Director for Projects Dianne Gove and Project Officer Ana Diaz participated in the sessions, facilitated discussions and prepared the minutes of the sessions.

14 July: Alzheimer Europe writes to Vice-President and Commissioner



Alzheimer Europe has written to the EU's Vice-President for Democracy and Demography, Dubravka Šuica (pictured, left), and the Health Commissioner, Stella Kyriakides (pictured, right). In the letters, Alzheimer Europe asks for dementia to be prioritised within EU policies, including the EU4Health programme, as well as work streams on ageing and demographics.

The letters explain that the progressive nature of dementia, coupled with the lack of a cure, no disease modifying treatment and a limited number of symptom-modifying drugs available, means that there is an imperative for healthcare systems and, more broadly, the societies and communities in which people with dementia live, to prepare and develop policy responses which provide support from the point of diagnosis through to the end of life.

In addition, Alzheimer Europe highlighted that the Dementia in Europe Yearbook 2019 had demonstrated the number of

people living within the EU would almost double to 14 million people by 2050, primarily as a result of ageing demographics.

Alzheimer Europe urged Commissioner Kyriakides to use her position, including during the trilogue negotiations, to accept amendments which will allow the EU4Health programme to provide a basis for the EU to support meaningful work to improve the lives of people with dementia, their families and carers across Europe.

In the letter to Vice-President Šuica, Alzheimer Europe urged her to acknowledge and identify dementia as a priority which must be addressed, both by the EU and Member States, across the domains of health, social policy and research, and as part of the EU's Green Paper on Ageing (which is currently under development),

Furthermore, the letter sets out the need for the EU4Health Programme to align with the Report on the Impact of Demographic Change and the Green Paper on Ageing, to ensure that the challenges the healthcare systems will face as a result of ageing demographics is addressed by EU and national health policies. Alzheimer Europe has also written to the Rapporteur and Shadow-Rapporteurs of the EU4Health programme, also asking them to prioritise dementia within the EU4Health programme.

We have since received a response – see p. 15 for details.

28 July: Alzheimer Europe calls for urgent action to address the impact of COVID-19 on dementia research



On 28 July 2020, following engagement with its national members, research funders and industry partners, Alzheimer Europe issued a position statement highlighting the pressure on dementia research as a result of COVID-19.

The pandemic has caused disruption to all aspects of life across the world, as measures aimed at slowing the spread of the virus (social distancing, lockdown, closing of places of work etc.) have interrupted normal ways of working. This is also true for researchers working in laboratory and clinical settings, where a multitude of overlapping issues (furloughing or redeployment of staff, closure of services etc.) have resulted in research and projects being put on hold.

In addition to these physical distancing restrictions, changes to funding and resources have also placed pressure on the dementia research community. Specifically, concerns around the funding of delayed research projects, the cancellation of future research calls and a shift in focus towards COVID-19 in research calls have added new challenges to the field.

As a result, research has slowed, impeding the ability of researchers to develop innovations to detect, diagnose, prevent and treat the underlying diseases which cause dementia. Furthermore, the cumulative impact of these challenges will have a significant impact upon researchers, particularly those at an early stage of their career.

To address these issues, the position statement sets out a number of recommendations aimed at both research funders (including governments and supranational bodies) and research institutions, grouped under three overarching themes:

- The need for greater support and flexibility for existing dementia research projects
- The impact on dementia research funding streams as a result of COVID-19
- The need to prioritise dementia in post-pandemic future research.

Recommendations include:

- EU to dedicate a specific strand of work to dementia research within the Horizon Europe framework programme for research & innovation (2021-2027).
- National research funders and governments to provide increased funding and resources for dementia research, in line with other conditions (e.g. other non-communicable diseases) and the ambitious aims set out in the 2013 G8 Communiqué.
- Research funders to show the maximum possible flexibility for funding recipients, to ensure resources can be allocated as required to allow for the completion of projects and to consider additional funding to support project extensions due to the COVID-19 pandemic
- National research funders should adopt an approach focused on prevention, care and cure, spanning the whole range of dementia research from fundamental science to care research

Commenting on the position statement, Alzheimer Europe’s Executive Director, Jean Georges, stated: “The COVID-19 pandemic has severely disrupted the innovative and promising research into dementia, undermining the progress made in dementia research to date. As dementia research is an area which has historically received proportionately less funding than related disease areas, these pressures have been felt even more intensely by researchers and research institutions, as well as by some research funders. That is why we call upon all governments, funding bodies and research institutions to

work together to ensure that the negative impacts of the pandemic are mitigated and that dementia is re-prioritised with the necessary resources and funds to improve our understanding of the underlying causes of dementia and our ability to provide the highest quality care and support to the 9.78 million people living with the condition in Europe.”

The full position statement can be accessed on the website of Alzheimer Europe:

<https://www.alzheimer-europe.org/Policy/Our-opinion-on/Dementia-Research-and-COVID-19>

6 August: Register now for the 30th Alzheimer Europe Online Conference!



Registration is now open for the 30th Alzheimer Europe Conference (#30AEC), taking place online from 20 to 22 October. Take advantage of the early bird registration fees until 15 September 2020, with a reduced registration fee of EUR 75 instead of EUR 125.

The full conference registration fee includes:

- admission to all sessions
- access to poster presentations
- access to chat rooms
- access to the videos after the conference.

Special rates are available for people with dementia, students, and members of Alzheimer Europe.

You can find more information about registrations, as well as the detailed programme and abstracts and profiles of our keynote speakers for this event, by visiting the conference section of our website:

<https://www.alzheimer-europe.org/Conferences/30AEC-2020>



Alzheimer Europe networking (online)

On 30 June, Owen attended a webinar hosted by the European Federation of Neurological Associations (EFNA) examining the place of neurological conditions in Covid-19 recovery planning, programmes and policies.

On 1 July, Angela attended a webinar for the DataSavesLives initiative.

On 1 July, Owen attended a meeting of the stakeholder group for the COVID-19 and mental health platform (part of the EU Health Policy Platform).

On 7 July, Owen participated in a meeting of the Core Group of the EU4Health coalition to discuss next steps in the group's work.

On 7 and 10 July, Dianne and Ana participated in the online meetings of the European Working Group of People with Dementia.

On 9 July, Jean and Ana had an exchange with the ADAIR project leadership.

On 9 July, Ana and Kate attended the PARADIGM project's online Patient Engagement Open Forum.

On 10 July, Dianne and Ana had a call with representatives of Roche.

On 13 July, Owen attended a webinar hosted by the Scientific Panel for Health, outlining their recommendations on the future of health research in the EU.

On 14 July, Jean attended the EFPIA webinar on health system readiness.

On 15 July, Owen attended an online meeting to relaunch the MEP Alliance on Mental Health.

On 16 July, Jean participated in the interim review for the VirtualBrainCloud project.

On 22 and 24 July, Jean attended a Biogen Advocacy Steering Committee.

On 23 July, Jean attended a meeting of the WW-FINGERS Network.

From 27-31 July, Angela, Cindy and Jean attended sessions of the virtual Alzheimer's Association International Conference (AAIC)

On 28 July, Angela attended a European Patients' Forum webinar on health data sharing.

On 29 July, Jean met with representatives of the World Dementia Council.

On 29 July, Jean and Cindy had an introductory call with the company Brainstorm.

On 30 July, Jean attended a Biogen webinar, "Planning for next phase of Alzheimer's".

On 4 August, Jean attended a stakeholder workshop of the JPI "More Years; Better Lives" on Ageing and Care Technologies.

On 5 August, Jean had a catch-up call with representatives from TauRx.

On 6 August, Owen met online with representatives of the WHO to discuss the Global Dementia Observatory Knowledge Exchange platform.

On 11 August, Dianne and Ana had a meeting with the Executive of the European Working Group of People with Dementia.

On 12 August, Jean met with representatives of Pfizer.

On 13 August, Angela attended a webinar on "National attitudes to dementia research", co-hosted by the Centre for Dementia Prevention and Alzheimer Scotland.

On 26 August, Dianne and Ana had a meeting with members of the DISTINCT project.



EU PROJECTS

23 June: Webinar on "Enhancing the early detection of Alzheimer's disease through digital technologies" held by AD Detect and Prevent consortium



Alzheimer's Disease
Detect & Prevent

The first Alzheimer's disease (AD) Detect and Prevent webinar entitled "Enhancing the early detection of Alzheimer's disease through digital technologies" was held on 23 June 2020. This online event brought together leading experts on AD and dementia to exchange views on the challenges and opportunities provided

by digital health solutions in enhancing the early detection of AD.

Approximately 80 participants, representing scientific societies, patient groups, academics and health stakeholders, joined the webinar.

The webinar started with a powerful testimony by Helen Rochford-Brennan, Chair of the European Working Group of People with Dementia (EWGPWD), in which she shared how AD has impacted her life and the lives of her family and loved ones. She also highlighted the importance of creating a culture in which people living with AD have a voice and are included in driving action on the illness. The testimony by Dr Rochford-Brennan was followed by three presentations by key opinion leaders: Prof. Masud Husain, Prof. Martin Rossor and Prof. Eric Salmon. Throughout their presentations, these experts shared their perspectives on the opportunities provided by digital technologies whilst also addressing some of the pitfalls associated with these emerging solutions.

An update on the development of the AD Detect and Prevent tool was presented near the end of the webinar by Prof. Masud Husain and Ulrik Ditlev Eriksen. As part of this presentation, they introduced the gamified “Starry Night” tablet task that uses stellar constellations to assess short-term memory. Moreover, Ulrik Eriksen explained the wider objectives of the project, including those related to risk detection and risk reduction, as well as the key challenges associated with early engagement, screening and lifestyle intervention that the digital health tool aims to address.

The full webinar can be accessed here:

<https://www.youtube.com/watch?v=ymjgm67bwAc>

Follow AD Detect and Prevent on [Twitter](#) and [LinkedIn](#) to stay updated on the latest project-related news.

29 June: The PRODEMOS project holds its General Assembly meeting



On 29-30 June, the Prevention of Dementia using Mobile Phone Applications (PRODEMOS) project held its General

Assembly (GA) meeting online. The project is aiming to make an evidence-based dementia prevention strategy using mobile Health (mHealth), accessible to those at increased risk of dementia.

The meeting commenced with Edo Richard welcoming almost 40 delegates. During the GA, partners received an update on the work carried out to date and work planned for the coming months, including the impact of the COVID-19 pandemic on the different project tasks. The ethical approval has been received in UK and China. During the first day, partners received an overview of the qualitative research work including pilot evaluations. The pilot study was completed in UK and is expecting to start in China by end August. The next session was then dedicated to the mHealth platform with a demonstration of the platform, which is now almost finalised. This was quickly followed up by an update on the systematic reviews conducted within WP2 (Strategies for dementia prevention) including the latest results. The first day was brought to a close with an update on management and finances.

Anders Wimo and Ron Handels started the second day with an update on the health economic aspects. During the session dedicated to the trial, each recruitment centre gave a status report on the study. Next, several scenarios were presented in term of recruitment and follow-up due to COVID-19. A very fruitful discussion took place and then Edo Richard drew the meeting to a close, thanking all the participants for their active contribution to the meeting.

Jean Georges and Cindy Birk represented Alzheimer Europe (AE) at the PRODEMOS general assembly meeting. AE is partner in the project and is involved in the coordination and

management, crossing cultural barriers and dissemination and communication work packages of this project.

<https://www.prodemos-project.eu/>

9 July: PARADIGM organises the third session of the Patient Engagement Open Forum (PEOF) series

On 9 July, the third session of the PARADIGM Patient Engagement Open Forum (PEOF) took place.



Participants were able to attend either one of the two parallel sessions (Session A, on Patient Engagement (PE) Tools developed by PARADIGM and session B “Motherhood should not be a fight”) or the three “flash presentations” (entitled the “Sustainability roadmap for the patient engagement ecosystem”, “Patient engagement agreements explained” and “Patient engagement in medicines R&D in the CEE region”).

Alzheimer Europe contributed to the Session on PE tools and presented part of the work developed by PARADIGM in the topic of Community Advisory Boards.

The presentations and recordings of all sessions are available at:

<https://patientengagementopenforum.org/>

10 July: RADAR-AD clinical study officially starts

The first participant to take part in the RADAR-AD study was included on 10 July in the project’s clinical site in Thessaloniki, Greece. This marked the official start of the RADAR-AD clinical study, despite a short delay due to the COVID-19 pandemic.



In the upcoming weeks the RADAR-AD consortium expects more inclusions to follow at its other clinical sites.

Read the full story:

<https://www.radar-ad.org/newsroom/official-start-radar-ad-clinical-study>

13 July: The EU Joint Act on Dementia project publishes a new article on the detection and diagnosis of neurocognitive disorders in nursing homes

On 13 July, a new article has been published in the European Medical Journal reporting the identification of facilitators to improve neurocognitive disorders (NCD) diagnosis in nursing homes.



Three countries (Bulgaria, France, Greece) participating in the “Act on Dementia” European Joint Action proposed to test telemedicine for NCD detection and diagnosis in six nursing homes. The experiments were implemented from April to June 2018.

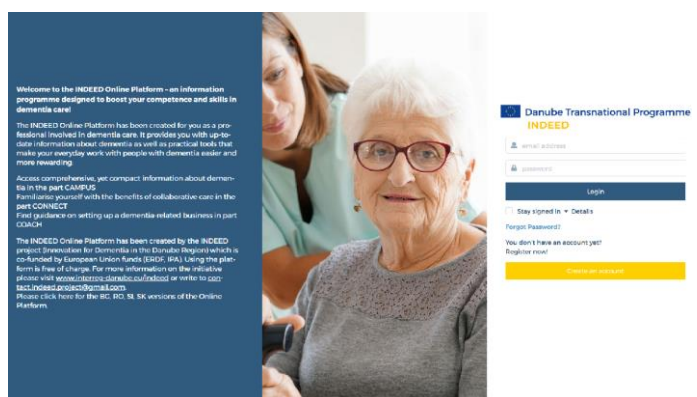
The six nursing homes were faced with various legal, ethical, and practical requirements before telemedicine could be implemented. Results at three months varied between the countries.

In Greece, the nursing homes’ staff was trained about NCD by a 30-hour tele-educational programme. In France, despite altered Mini-Mental State Examination (MMSE) scores and current telemedicine for behavioural disorders, there were few requests for NCD diagnosis, probably a result of unawareness of benefits of diagnosis for nursing homes’ residents. In Bulgaria, nursing homes’ staff training and 17 teleconsultations for NCD diagnosis took place and led to mild-to-major NCD diagnosis, including aetiological diagnosis in 16 cases. Despite the challenges, all the nursing home teams were satisfied with telemedicine. The dementia attitude scale results were similar between the different nursing homes, countries, and health professionals and other nursing homes’ professionals.

Each country identified facilitators to improve NCD diagnosis in nursing homes, e.g., a shared tool explaining the benefits of NCD aetiological diagnosis for nursing homes’ patients to be included in the NCD educational programme for nursing homes’ staff and general practitioners.

<https://bit.ly/3gzkAmh>

21 July: INDEED project launches online learning platform to advance knowledge of dementia care among health and social care professionals



The INDEED project launched its online learning platform on 21 July. The platform aims at upskilling professionals and entrepreneurs from the health and social field in regards to dementia. It is mainly aimed at general practitioners (GPs), nurses, social workers, physical/occupational therapists, neurologists, psychologists and service providers (e.g. "meals on wheels" or "Alzheimer Cafés").

The new platform has three distinct aspects:

- CAMPUS contains information about dementia as well as person-centred and holistic approaches in dementia care.
- CONNECT shares information about inter-professional collaboration and shared care plans.
- COACH is about how to set-up dementia-related services from a business perspective.

Using animated videos, texts, charts, infographics, interview-videos and quizzes, the online platform aims to support professionals in rural areas with limited access to face-to-face trainings. Given the current restrictions for professional trainings due to COVID-19, the online format of INDEED's training may be particularly useful for professionals seeking to advance their knowledge in the area of dementia care.

The INDEED project designed the platform to be fully in line with international medical standards and to support national dementia plans in South-Eastern Europe. In early autumn, the online platform will be available in Bulgarian, Romanian, Slovakian and Slovenian.

The platform, which is freely accessible, can be found here:

indeed-project.eu

You can view a screencast of the online platform here:

<https://www.youtube.com/channel/UC3rZE1u4ljAYMkX9gRrJGgw>

31 July: EPAD publishes its project newsletter

On 31 July, the European Prevention of Alzheimer’s Dementia (EPAD) project released



its external newsletter and reported the important advances that have been made during the past quarter. Although the IMI period of EPAD has come to an end for many members in June and the rest of them in October, the aims, objectives and vision of EPAD persists. National programmes are being developed to follow up all the EPAD participants in a series of linked national and local programmes.

During the past quarter, the EPAD members released to the world the V1500.0 dataset and are planning to release the entire EPAD dataset to the partnership in September. Lucy Stirland (University of Edinburgh, UK) has been awarded the 2020 Porto Research Award from the European Federation of Psychiatric Trainees (EFPT) for her paper using EPAD V500.0 data, published last year in the Journal of Alzheimer's Disease.

The newsletter also includes the important advances and major achievements made by each Work Package during the lifespan of the project.

You can read and subscribe to the newsletter here:

<https://bit.ly/3jqRA1A>

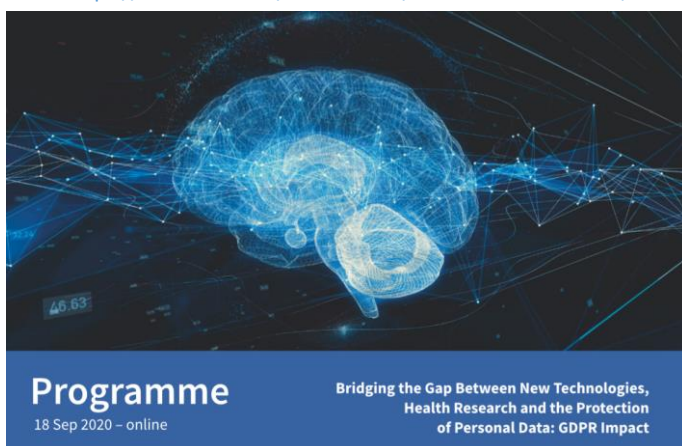
1 August: Registrations open for the public TVB-Cloud conference on the GDPR, AI and health technologies

The Department of Innovation and Digitalisation in Law at the University of Vienna recently opened registrations for a 1-day

conference on the General Data Protection Regulation (GDPR), held within the framework of the VirtualBrainCloud project. The virtual conference, entitled “Bridging the gap between new technologies, health research and the protection of personal data”, will be held on 18 September, and is free of charge and open to the general public.

Data privacy and the GDPR are particularly important concerns for the VirtualBrainCloud (TVB-Cloud), a Horizon 2020-funded project which is aiming to create a decision support system that will give clinicians access to multidisciplinary data on neurodegenerative disease via a cloud-based, personalised brain simulation platform. The conference will address the regulatory framework and use of new information technologies in the healthcare sector, with a particular focus on patient privacy and data protection. In addition, it will address the use of artificial intelligence (AI) in clinical research projects such as TVB-Cloud, featuring presentations from interdisciplinary experts working on the Human Brain Project and at the European Institute for Innovation through Health Data (i~HD), among others. To view the programme and register for the conference, please visit:

<https://id.univie.ac.at/aktivitaeten/tvb-cloud-conference/>



3 August: ROADMAP project ethics paper accepted for publication in Journal of Alzheimer’s Disease



A paper on the ethics of predictive modelling in Alzheimer’s Disease (AD), authored by the ROADMAP project’s ethics work package (WP8) has been accepted for publication in The Journal

of Alzheimer’s Disease.

ROADMAP ran from September 2016 till October 2018 and Alzheimer Europe was a partner in this project. Dianne Gove, Director for Projects, Alzheimer Europe co-authored this new publication. We will be sure to share the link once it has been published online.

The “Real world Outcomes across the Alzheimer’s Disease spectrum for better care: Multi-modal data Access Platform” (ROADMAP) project aimed to provide the foundation for an integrated data environment and framework for real-world

evidence (RWE in Alzheimer’s disease). This included the development of consensual key outcome measures and enabling data integration tools for dataset characterisation and outcome classification, as well as guidelines on the handling and interpretation of RWE data.

13 August: Neuronet to host an ECR session as part of its 2020 Public Event at #30AEC

In 2019, the Neuronet Sessions introduced the projects of the Innovative Medicines Initiative (IMI)



neurodegeneration portfolio to a broad audience composed of people with dementia, caregivers, patient associations, researchers and clinicians. This year, Neuronet is expanding the focus of its public event, which will be held as part of the Alzheimer Europe annual conference between 20-22 October.

Neuronet is an IMI-funded coordination and support action designed to act as a key enabler and mediator for the IMI neurodegeneration portfolio, which includes projects such as EPAD, PHAGO, ROADMAP and ADAPTED among others. During the 2020 Neuronet Sessions, IMI project collaborators will present their work on data sharing, ethics and regulatory interactions. In a Roundtable session, IMI project leaders will address the challenges experienced by public-private partnerships during the COVID-19 pandemic, discussing how research will evolve in the critical post-COVID period.

Neuronet is also dedicating a session to early-career researchers (ECRs) working on IMI projects, designed to showcase the breadth and depth of IMI-funded neurodegeneration research as well as the diversity of project collaborators involved. All ECRs (defined as graduate students or researchers within 10 years of completing their graduate studies) working on the 18 projects in the IMI neurodegeneration portfolio are invited to submit abstracts via the online abstract submission portal.

<https://www.imi-neuronet.org/2020-virtual/>

24 August: RADAR-AD researcher Sébastien Libert shares findings from ethics interviews with members of the Patient Advisory Board

Earlier this year Federica Lucivero and Sébastien Libert from the University of Oxford conducted interviews on ethical and social perspectives towards the research done in RADAR-AD, with members of the project’s Patient Advisory Board (PAB) (read the project’s news story about it [here](#)).

In an interview published this summer on the RADAR-AD website, Sébastien Libert (pictured) talks about the highlights



of their research, the significance and main findings from these interviews and elaborates on the impact of the COVID-19 crisis on this part of the research for RADAR-AD.

Read the interview with Sébastien Libert:

<https://www.radar-ad.org/newsroom/radar-ad-researcher-sébastien-libert-shares-findings-ethics-interviews-members-pab>

26 August: AMYPAD members restart trial recruitment and continue to work on data analysis

In its August newsletter, the Amyloid imaging to prevent Alzheimer's disease (AMYPAD) project reported that both of its studies have been impacted by the COVID-19 pandemic.

AMYPAD Diagnostic and Patient Management Study (DPMS):

The COVID-19 pandemic has impacted recruitment of new participants (9 participants in Q2 2020 vs 118 in Q1 2020). The recruitment period between January and February 2020 was very productive. However, from March the AMYPAD team has observed a drastic decrease in the recruitment of patients in all eight active sites due to the COVID-19 pandemic. Recruitment stopped in all sites from the second week of March to the end of April. Starting from May, recruitment has slowly restarted in some countries. As of August 24th, 2020, 780 patients have been included and 616 scans performed (including 26 repeated scans). The recruitment will be able to resume in all eight sites once the situation has stabilised, with an expected delay to reach the 900 patients.

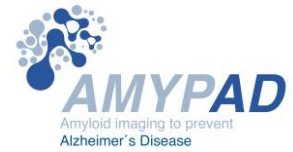
AMYPAD Prognostic and Natural History Study (PNHS):

Recruitment activity within the AMYPAD PNHS had also stopped during the COVID-19 crisis. This was due to the closure of sites and cessation of research visits. Consequently,

the past months have seen slow progress within the PNHS in terms of recruitment. By June 2020 some AMYPAD PNHS sites had slowly started to resume recruitment, always taking into account local and national measures concerning safety and distancing. Of the 17 active sites in the PNHS, 12 sites have been able to resume recruitment, although at reduced capacity. It was expected that all sites could restart their activities in September; however, the current developments with COVID-19 could cause another period of site closures and slow activity. Despite the difficulties, the PNHS has now reached 600 subjects consented, coming from six different Parent Cohorts.

Despite the recent low recruitment into both studies, the AMYPAD teams have continued to analyse images from external cohorts as well as starting to analyse images from both AMYPAD studies. The team was also excited to be chosen for a 'Featured Research Session' at the virtual Alzheimer's Association International Conference (AAIC) in July with a topic covering 'The value of amyloid PET beyond dichotomization' and presentations from Isadora Lopes Alves, Lyduine Collij, Santi Bullich and Jose Luis Molinuevo. Over the coming months, the consortium is planning its annual General Assembly meeting as it enters into its fifth and final year of AMYPAD so the discussions will be focusing on analysis plans, pivotal publications and completing final milestones as well as addressing topics such as data access and sustainability. You can read the newsletter here:

<https://mailchi.mp/61fc98d00456/amypad-newsletter-august-2020>



EU project acknowledgements



A number of the projects in which Alzheimer Europe is a project partner receive funding from Horizon2020 or from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA. The projects in this newsletter are:

AD Detect & Prevent - grant agreement 820636

AMYPAD - grant agreement 115952

EPAD - grant agreement 115736

Neuronet - grant agreement 821513

PARADIGM - grant agreement 777450

PRODEMOS - grant agreement 779238

RADAR-AD - grant agreement 806999

ROADMAP - grant agreement 116020

VirtualBrainCloud - grant agreement 826421

Members of the European Alzheimer's Alliance



Currently, the total number of MEPs in the Alliance stands at **94**, representing **26** Member States of the European Union and six 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: Monika Vana (Greens/EFA). **Belgium:** Petra de Sutter (Greens/EFA); 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); Ruža Tomašić

(ECR). **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 Alamestä (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 Spyraiki (EPP); Elissavet Vozemberg-Vrionidi (EPP). **Hungary:** Tamás Deutsch (EPP); Ádám Kósa (EPP). **Ireland:** Barry Andrews (ALDE); Matt Carthy (GUE/NGL); Deirdre Clune (NI); Ciàran Cuffe (Greens/EFA); Clare Daly (GUE/NGL); Frances Fitzgerald (EPP); Luke 'Ming' Flanagan (GUE/NGL); Billy Kelleher (Renew Europe); Seán Kelly (EPP); Mairead McGuinness (EPP); Grace O'Sullivan (Greens/EFA). **Italy:** Isabella Adinolfi (NI); Brando Benifei (S&D); Pierfrancesco Majorino (S&D); Aldo Patriciello (EPP); Patrizia Toia (S&D). **Lithuania:** Vilija Blinkevičiute (S&D). **Luxembourg:** Charles Goerens (Renew Europe); Christophe Hansen (EPP); Tilly Metz (Greens, EFA); Nicolas Schmit (S&D); 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); Cláudia Monteiro de Aguiar (EPP); Manuel Pizarro (S&D). **Romania:** Cristian-Silviu Busoi, MEP (EPP); Marian-Jean Marinescu (EPP). **Slovakia:** Ivan Stefanec (EPP). **Slovenia:** Franc Bogovič (EPP); Milan Brglez (S&D); Tanja Fajon (S&D); Klemen Grošelj (Renew Europe); Irena Joveva (ALDE); Romana Tomc (EPP); Milan Zver (EPP). **Spain:** Izaskun Bilbao Barandica (Renew Europe); Rosa Estarás Ferragut (EPP); Juan Fernando López Aguilar (S&D); Diana Riba i Giner (Greens-EFA); Ernest Urtasun (Greens/EFA). **Sweden:** Jytte Guteland (S&D); Peter Lundgren (ECR).



EU DEVELOPMENTS

1 July: Germany takes over Presidency of the Council of the European Union



On 1 July, the Germany formally took over the rotating Presidency of the Council of the European Union, taking over the

position from Croatia. As part of this, Germany published its programme of work, outlining its priorities during its six-month tenure, setting out the following guiding principles:

- Overcoming the COVID-19 pandemic permanently, as well as the economic recovery
- A stronger and more innovative Europe
- A fair Europe
- A sustainable Europe
- A Europe of security and common values
- A strong Europe in the world.

The German Presidency has identified ensuring the rapid conclusion of the negotiations on the EU's multiannual financial framework (MFF) for the period from 2021 to 2027 as a key priority. Specifically, it has noticed that the MFF must be geared to the current challenges in relation to the COVID-19 pandemic, whilst also addressing the long term strategic goals of the European Union. Full details of the programme of work for the German Presidency can be found at:

<https://www.eu2020.de/eu2020-en/programm>

10 July: European Parliament passes motion on the future of the EU's public health strategy post-COVID-19

On 10 July, the European Parliament adopted a resolution by 526 votes



European Parliament

to 105 (with 50 abstentions), setting out its view of the principles which should underpin the EU's future public health strategy post-COVID-19.

In a plenary debate with Health Commissioner Stella Kyriakides and the Council (on 7 July), MEPs highlighted the need for on the EU's public health strategy to learn lessons from the COVID-19 crisis, with a number of MEPS arguing for the EU to play a greater role in area of health.

Furthermore, MEPs underlined the need to ensure that health systems across the EU are better equipped and coordinated to face future health threats, as no member state can deal with a pandemic such as COVID-19 alone.

The resolution contains over 50 points, including recommendations and calls for action, primarily aimed at the European Commission, including:

- Calling on the Commission to propose a directive on minimum standards for quality healthcare, based on stress testing
- Calling on the Commission to integrate adequate funding of the healthcare system and well-being indicators within the country-specific recommendations as part of the European Semester process
- Calling for an EU Action Plan 2021-2027 on mental health, with equal attention being paid to the biomedical and psychosocial factors of ill mental health
- Calling for an EU Action Plan on healthy ageing to enhance the quality of life of older people

- Calling on the Commission to present a proposal on improving the independent financing of European patient groups.

You can watch the debate (including the speech by Stella Kyriakides) here:

<https://bit.ly/32yjsKH>

You can read the text of the resolution here:

https://www.europarl.europa.eu/doceo/document/RC-9-2020-0216_EN.html

21 July: European Council reaches agreement on the EU recovery instrument and long-term budget



Council of the European Union

On 21 July, after four days of talks by leaders of the EU27 countries, the European Council reached an agreement on the recovery instrument (Next Generation EU) and the future long budget of the EU (the Multiannual Financial Framework).

The fund allocates EUR 750 million of funding for NGEU, with EUR 1,074 billion allocated for the MFF. Of particular relevance for the European dementia movement:

- Within the NGEU, EUR 5 billion was allocated to the Horizon Europe programme. However, this was a reduction of EUR 8.5 billion from the European Commission's proposal
- Funding in the recovery instrument for the EU4Health programme was completely removed from NGEU
- In the MFF, Horizon Europe was allocated EUR 75.9 million, down from the EUR 80.9 billion proposed by the Commission
- For the EU4Health programme, EUR 1.67 billion has been allocated, which is broadly consistent with the Commission's proposal.

The next stage of the process will be focused on the trilogue negotiations (between the Commission, Council and Parliament), with the Parliament having the decisive vote, which is expected to take place sometime in autumn. The full text of the Council conclusions can be found here:

<https://www.consilium.europa.eu/en/press/press-releases/2020/07/21/european-council-conclusions-17-21-july-2020/>

21 July: European Research Council pulls support for cOAlition S open access plan



The governing body of the European Research Council (ERC) has withdrawn its support for the cOAlition S, a multi-stakeholder movement which seeks to implement open access to scientific papers, whereby they would be free to access and share at the point of publication.

Plan S, the strategy aimed at implementing open access, is due to be published in 2021. Research funding bodies that have signed-up include the World Health Organization, the Wellcome Trust, the Bill & Melinda Gates Foundation, as well as 17 national funding agencies.

Having previously participated in cOAlition S, the ERC Scientific Council has released a statement indicating that it will work towards open access of scientific papers in a different way and has therefore withdrawn as a supporter of cOAlition S.

The statement explains that the ERC wishes to pay closer attention to a number of issues, including the needs of researchers and preserving equity among research communities and among European countries.

In particular, the ERC noted that the intention of cOAlition S to regard the publication of research results in hybrid venues as 'non-compliant' from 1 January 2021, would be detrimental for early career researchers, researchers working in countries with fewer alternative funding opportunities or working in fields in which open access policies are more difficult to implement.

The full statement of the ERC can be read here:

<https://erc.europa.eu/news/erc-scientific-council-calls-open-access-plans-respect-researchers-needs>

23 July: European Parliament passes resolution on European Council budget agreement

On 23 July, the European Parliament adopted a resolution by 465 votes to 150 (with 67 abstentions), responding to the European Council's political agreement on the future budget of the EU.

The resolution followed the political agreement of the European Council on 21 July, setting out the future of the EU recovery instrument (Next Generation EU) and the long-term budget (Multiannual Financial Framework).

During a plenary debate which included speeches from both the Commission President, Ursula von der Leyen, and President of the European Council, Charles Michel, MEPs were critical on a number of issues of the agreement, including criticising the decision to reduce funding for programmes such as EU4Health and Horizon Europe.

The resolution outlined that the European Parliament does not accept the European Council's political agreement on the 2021-2027 MFF in its current form and that they are prepared to withhold their consent until a satisfactory agreement is reached. In particular, the text states that the "proposed cuts to health and research programmes are dangerous in the context of a global pandemic".

The resolution explains that the Parliament will negotiate with the Council in relation to the points within the resolution and calls for an agreement to be reached by October 2020, to allow for a smooth transition to new programmes from 1 January 2021.

You can watch the debate here:

https://multimedia.europarl.europa.eu/en/plenary_20200723-0900-PLINARY_vd

You can read the text of the resolution here:

https://www.europarl.europa.eu/doceo/document/TA-9-2020-0206_EN.html

18 August: Alzheimer Europe receives response from Vice-President and Commissioner



Following letters sent to the Vice-President for Democracy and Demography, Dubravka Šuica, and Health Commissioner, Stella Kyriakides, Alzheimer Europe has received a joint

response from the offices of both officials.

In its letters to the Vice-President and the Commissioner, Alzheimer Europe raised a number of matters, including:

- The numbers of people living with dementia in Europe and the projected increase by 2050, as outlined in Alzheimer Europe’s Dementia in Europe Yearbook 2019
- The need for improvement in the availability, suitability and affordability of services and supports for people living with dementia and their carers
- The need for the EU4Health programme to include measures to support people with dementia
- Urging both Commissioner Kyriakides and Vice-President Šuica to work closely together on the overlapping matters relating to health and the ageing demographics of Europe.

The response of the offices of the Vice-President and the Commissioner was broad in scope, without committing to any specific measures for dementia at a European level. The letter:

- Acknowledges of the figures provided by Alzheimer Europe in relation to the number of people living with dementia and the projected increase in numbers
- Points to the importance of Alzheimer Europe’s member organisations in prioritising dementia at a national level (owing to the reserved competence of Member States in relation to health matters)
- Recognises the importance of health policy and long-term care in relation to the EU’s work on ageing
- Restates some of the existing areas of focus of the EU Commission, including a recently published Commission Communication on COVID-19 and a dedicated section on mental health and COVID-19 on the EU’s Health Policy Platform.



MEMBERS’ NEWS

8 July: Association Luxembourg Alzheimer mourns founding member Paul Diederich



The Board of Directors and staff of Association Luxembourg Alzheimer (ALA) are in mourning for founding member, long-time president and honorary president, Paul Diederich.

The association has paid tribute to Mr Diederich, highlighting his tireless efforts advocating for people with dementia. He will be greatly missed and the ALA will continue its work in his honour. Both Alzheimer Europe and Association Luxembourg Alzheimer express their deepest sympathies to the Diederich family.

21 August: The Alzheimer Society of Ireland’s “Dementia: Understand Together” campaign is helping to change dementia culture in Ireland

With COVID-19, recent months have been challenging for us all. For people with dementia, they have been especially so. Many have been cocooning or staying at home to minimise the risk of contracting COVID-19. To protect people with dementia from COVID-19, some services had to change, and many have been missing important social connections and activities that are so crucial for wellbeing.

The international theme for World Alzheimer Month (September) is “Let’s talk about dementia” and this is especially poignant as stigma and misunderstandings of dementia are still prevalent in Ireland. Now, more than ever, it is vital to change the current culture around dementia and help create an Ireland that supports and includes people living with dementia.

Changing a culture takes time, but it is often the little things that make the biggest difference in a person’s life, such as:

- see the person, not the dementia
- talk about dementia
- ask how you can help
- stay in touch
- support the person to keep up hobbies and interests
- make sure your space or service is easy to use.

Over 40 national organisations and 340 Community Champions have joined the Dementia: Understand Together campaign, and are doing just that. One example is Irish Rail which organised various dementia awareness initiatives, including training for staff and workshops with people with dementia to explore their travel experience and how that can be enhanced.



Kevin Quaid (pictured, on the far left of the group photo), Vice Chairperson of the Irish Dementia Working Group (IDWG) and living with Lewybody dementia, says “knowing staff have received training in dementia and seeing staff members wearing the Dementia: Understand Together badge makes me feel safe and enables me to travel alone. A little understanding can go a long way.”

Understanding dementia and looking at how to make services and activities accessible to people with dementia is vital to creating inclusive communities. Awareness training can be a first step. Local community champions work hand in hand with organisations, councils and local businesses to raise awareness of dementia, hold information talks, create inclusive services and inspire choirs, sports and other community groups to embrace people with dementia.

Find out more at:

<http://www.understandtogether.ie/get-involved/>

24 August: Karelleion Alzheimer association shares findings regarding use of touch-screens in occupational therapy for people with dementia



The “Karelleion” Integrated Alzheimer and related disorders Unit of the “Apostoli” charitable organisation of the Holy Archdiocese of Athens - a member of the Panhellenic Federation of Alzheimer’s Disease and Related Disorders - reports on its approach

to occupational therapy and rehabilitation of cognitive and perceptual skills of patients with dementia, using PCs with touch-screens:

Activities on computers equipped with touch-screens can be an important tool, during the therapeutic process, in order to cope with the symptoms of dementia.

There are studies that suggest and promote the use of a PC with a touch-screen by older people, which show how useful and easy it is to use this technology, especially when there is a decline of cognitive and motor skills. The touch-screen user is not just looking at the screen but interacts with it, as well.

Interactive applications on the touch-screen offer a new, creative approach to therapeutic intervention, which may enhance a person’s memory as well. Practice of the “executive” memory through technological activities, strengthens the user, helping to maintain and improve their memory’s functionality. A good level of concentration and visual-kinetic coordination is required, in the use of mouse and keyboard. In case of cognitive disorders, there is difficulty in handling it and in performing the command.

In people with dementia, the skill of learning is improved when accompanied by an action, such as a touch-screen PC.

Examples of applications:

- Copy a drawing on the touch-screen to practice the executive functions.
- Find a difference between almost two identical photos, for exercise of attention and visual discrimination.

Observations and results:

- All participants expressed positive feedback regarding ease of use.
- Group sessions (groups of 2-3 people) enabled participants to interact with each other.
- They improved their self-confidence.
- They were creating topics for discussion, concerning this new kind of technology.
- They were continuously improving their functional skills, in how to use the display.
- Individual sessions improved the trust between therapist and patient.

Activities in a PC with touch-screen, may prove to be beneficial, in the following areas:

- orientation in place and time
- creation of a pleasant environment
- improvement of learning skills
- information retrieval and visual memory
- better relationship between healer and patient
- audio-visual coordination.

24 August: At halfway point, Erasmus “Bridge” project has created 8 “serious games”, aiming to act on dementia symptoms, reports Panhellenic Federation



The Erasmus+ funded Bridge project is taking an intergenerational approach, aiming to create serious games acting on dementia symptoms. The project is now in its central phase, reports the Panhellenic

Federation of Alzheimer’s Disease and Related Disorders.

The Bridge partnership is pleased to announce that eight games, acting on cognitive and behavioural symptoms of dementia, have been created and are ready to be tested. These games have been designed and produced by the project consortium, based on the concept ideas of health professionals, game-designers, young volunteers, people with dementia and their caregivers coming from Greece, Italy and Romania.

1. “Blooming flowers” is a cooperative board game in which players have to collaborate in order to create beautiful bouquets of flowers. The game aims to enhance social skills, memory, observation, concentration and other cognitive skills.
2. “Specialites” is a cooperative board game aiming to enhance cognitive, social and behavioural skills, in which players collaborate to create a recipe.
3. “Emotions” is a storytelling phygital game that aims to stimulate emotional recognition and reminiscence, in which all players try to guess the emotions of a sound, recall and tell a story about it.
4. “The Directors” is a cooperative board game in which all players try to create a theatrical play based on the scenario of the game. Players have to select the proper actors, movements and objects for scenery and songs.
5. “Find it” is a digital game in which players are asked to recognise the negatives of images or to select the part of the image that has to be cut. It stimulates observation, critical thinking, creativity and attention.
6. “Next destination” is a digital game where the player has to prepare the luggage for different destinations. It stimulates observation, memory, critical thinking and concentration.
7. “Bird watching” is a digital game in which players pretend to be birdwatchers, having to find and identify specific birds based on a model. It stimulates memory, attention,

observation and concentration and it includes different levels of difficulty.

8. “Flea market» is a digital game in which the player visits a neighbourhood flea market to do some shopping. Money management, memory and critical thinking are the main skills enhanced by the game.

<https://projectbridge.eu/>

24 August: Deutsche Alzheimer Gesellschaft introduces its new video on “Driving and Dementia”

For many people, driving oneself means independence and the ability to participate in a variety of activities. Dementia increasingly affects the ability to drive, but those affected often do not want to give up this form of mobility.



A new video by the Deutsche Alzheimer Gesellschaft (DAIzG), the German Alzheimer association, shows different ways of dealing with conflicts on this topic. The video contains a mixture of animated cartoons and interviews with family caregivers.

It has been produced as a project of the initiative Demenz Partner (Germany’s “Dementia Friends” programme) and can be seen on the homepage www.demenz-partner.de and on the DAIzG YouTube channel:

www.youtube.com/c/DeutscheAlzheimerGesellschaft

The video is in German, with subtitles in different languages created by YouTube

25 August: Alzheimer Turkey introduces “Digital Grandchild” project

The Turkish Ministry of Education recently started an initiative for high school students, named “Go easy with AGE” with the aim of supporting the memory, communication and motor skills of older people, for the purpose of inclusion. One of the high schools in İzmir was first to join the project and they started their process in collaboration with the İzmir Branch of Türkiye Alzheimer Derneği



(Turkish Alzheimer's association). Within the scope of this study, volunteer students from the school met regularly with people living with dementia and during the meetings, young and old people chatted, painted together and carried out activities to improve visual memory.

When the COVID-19 lock-down for age 65+ (considered to be “at risk”) started, the Association had to cease activities, following which, some families reported that their relatives with dementia were getting very bored at home and that their discomfort progressed. Upon this, the project evolved into a digital activity and emerged with the title "Digital Grandchild". High school students in Izmir contacted the people with dementia with whom they had previously been meeting face-to-face on a weekly basis, via video and telephone calls, while they could not leave their homes, to maintain and increase the bond they had create. The people with dementia in question were very happy to speak to the young people via mobile telephone. The project name emerged from the fact that these volunteers became like their grandchildren, some even giving their “grandchildren” an affectionate kiss, on the screen.

While some of the young people were uneasy at first, after they witnessed the joy they were bringing, they were happier and more motivated to participate. The project is also beneficial for the young people involved, by contributing to the development of social responsibility awareness and as a reference for their academic careers.

During the course of their conversations, students also inform the older people they are in contact with about social media, and make videos explaining how to use technology. This method of communication, which started on in March 2020 with 11 students in Izmir and continued during the feast of Ramadan, has now become a normal part of life today, for those involved.

The success of the “Digital Grandchild” project has inspired plans to expand it to all regions of Turkey and even to Turkish people living abroad.

In the extended version, where the students who will volunteer, do not have the opportunity to meet face to face with their grandparents, the flow process will be as follows:

- young people make short videos, presenting themselves and/or presenting a skill, singing, playing guitar, reading fairy tales, etc. to introduce themselves;
- they share this video with Türkiye Alzheimer Derneği, to be forwarded to the relatives of the person with dementia;
- the people with dementia and their relatives watch these videos a couple of times to enable them get to know the young person and to feel bonded;
- when the person with dementia feels ready, their contact information is forwarded to the student who will be the “grandchild”;
- the volunteer will be expected to call the Association on a regular basis.

As with all volunteer work, discipline and regularity are very important in this project. It is very important to meet reasonable requests from the families, to call at the promised time, and to treat all participants with respect, kindness and compassion. To try to ensure this, a training is given to volunteers about the disease, and to inform them about some “do’s and don’ts” before they start.

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POLICY WATCH

24 July: CEAFA express disappointment at lack of progress in social care reform in Spain



Confederación Española de Alzheimer (CEAFA) has issued a statement expressing disappointment that the Spanish Congress of Deputies has been unable to take forward recommendations on the reform of social policies and the system of care.

The statement explains that the recommendations produced by the Commission for Reconstruction had not attracted sufficient political consensus and therefore would not be reflected in the future social care reforms.

CEAFA notes this decision will have the greatest effect on older people and the most vulnerable in society, including people with dementia. It is further highlighted that this population group has experienced significant challenges as a result of the COVID-19 pandemic, including:

- More than 19,000 older people having died in residential homes as a result of COVID-19 or symptoms related to the disease, with nursing homes have having become one of the main sources of infection
- The excess mortality rate in March and April 2020, for people receiving a service or benefit from the Dependency Care System, standing at 21,621 excess deaths (compared to the same period last year)
- The pandemic affecting the economic and labour field, exacerbating the complicated family and professional circumstances of informal caregivers.

Additionally, the statement highlights that families and caregivers are key to providing support for people with dementia, but are often affected by the consequences. It notes that the majority of informal caregivers are woman and aged over 50, with many informal carers partially or totally giving up their job during the period of caregiving. The average period spent providing care is nine years, with an average cost of caring for a person with Alzheimer's disease of EUR 35,000 per year.

In addition to referencing the commitment of the Spanish National Alzheimer's Plan, CEAFA noted that they had hoped lessons would be learned from the effect of the pandemic on people with Alzheimer's and dementia, including the importance of:

- Early diagnosis for dementia
- Adequate social and health coordination
- Strengthening of the care system
- Social protections of informal caregivers.

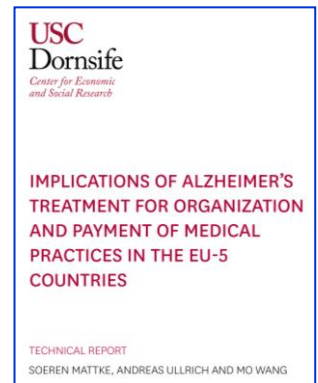
The statement concludes by noting that the measures proposed within the draft conclusions of the Social Policies and Care System Group were a starting point and that the lack of consensus among the political groups is a major obstacle to the development of a new social policy. The full statement of CEAFA can be read here:

<https://bit.ly/32FlszM>

30 July: New study examines medical treatment and costs in the USA and Europe

During the Alzheimer's Association International Conference (AAIC), researchers from the University of Southern California (USC) shared findings from their research examining the medical treatment and costs associated with treating Alzheimer's disease.

Soeren Mattke, Andreas Ullrich and Mo Wang of the Center for Economic and Social Research



(CESR) at the USC Dornsife College of Letters, Arts and Sciences, assessed the hurdles to providing treatments to people with Alzheimer's in the United States, as well as in France, Germany, Italy, Spain and the United Kingdom.

Split into two reports (one for the USA and one for Europe), the research considers what healthcare systems could do to prepare for the introduction of a novel disease modifying treatment. In addition, the reports detail the stages of a person with Alzheimer's disease from the point of diagnosis, assessing the system-wide obstacles to the introduction of a disease-modifying treatment and how these challenges might be overcome.

The report for Europe highlights a number of encouraging examples of existing practice, including:

- A national network of memory clinics for routine care and research in France
- Annual comprehensive geriatric assessment including memory complaints in Germany
- A national expert group and dementia observatory to track progress and data in Italy
- A Centres of Excellence based approach to memory care in Spain
- Co-location of memory services in acute care hospitals for access to procedural skills and infrastructure in the UK.

However, it also identifies the need for countries to devote additional resources to memory care, engage primary care physicians in case-finding and triage, and make use of clinical specialists' time more effectively. Other challenges identified across the six countries include:

- Dementia strategies produced by countries tend to be unfunded

- Countries having limited capacity to conduct PET scans to diagnose Alzheimer’s disease
- Where capacity does exist in healthcare systems, there are few incentives to make use of it
- The capabilities to deliver high-quality memory care are limited, mainly related to issues around workforce.

The report for the report examining the USA can be found at:

<https://cesr.usc.edu/sites/default/files/ADUS.pdf>

The report for the report examining the EU5 countries can be found at:

<https://cesr.usc.edu/sites/default/files/ADEU.pdf>

The research was funded by a contract from Roche, known as Genentech in the United States, a company that is developing blood-based assays and disease-modifying treatments for Alzheimer’s disease, to the University of Southern California. The sponsor had no role in the design of the study, interpretation of the findings and decision to submit the data for presentation at AAIC.



AAIC WATCH

We present some highlights emerging from this year’s Alzheimer’s Association International Conference (AAIC), held online, from 27 to 31 July 2020.



27 July: The IDEAS study reports that amyloid PET scans had a small impact on rates of hospitalisations and fails to meet its pre-specified endpoint



On 27 July, Dr Gil Rabinovici from the University of California in San Francisco (US) gave a talk at the virtual Alzheimer’s Association International Conference. His talk was entitled “Association Between Amyloid PET and Health Outcomes: the IDEAS Study”. He presented the top-line results of the second phase of the IDEAS study.

The aim of the study is to determine the clinical usefulness on patient-oriented outcomes of a brain positron emission tomography (PET) scan that detects amyloid plaques, a core feature of Alzheimer’s disease. The first phase of the IDEAS study reported that amyloid PET scans changed the treatment plans in two-thirds of the cases of the 11,409 people who underwent amyloid scans.

First results of the second phase of the study showed that amyloid PET scans were associated with a 4.5% relative reduction in hospitalisations in the year after the scan compared to the control group. The study missed the pre-specified endpoint as it did not meet the 10% reduction goal. The difference in hospitalisations was driven by people with dementia and not those with mild cognitive impairment. In addition, it was reported that both people with dementia and mild cognitive impairment who had a positive amyloid scan were 22% less likely to be hospitalised in the next year than those with negative scans. Researchers are still analysing the data.

Dr Gil Rabinovici concluded his talk by presenting the next IDEAS study that will recruit a diverse cohort including at least 2,000 blacks and 2,000 Latinos among the 7,000 planned participants. The study is expecting to start this fall.

<https://www.alzforum.org/news/conference-coverage/ideas-finds-small-drop-hospitalizations-missing-goal>

27 July: New research reports that Flu and pneumonia vaccines may reduce risk of Alzheimer’s dementia



Three research studies presented at the Alzheimer’s Association International Conference (AAIC 2020) on 27 July suggested that flu (influenza) and pneumonia vaccination are associated with a lower risk of developing Alzheimer’s dementia.

The first study, conducted at the McGovern Medical School at the University of Texas Health Science Center in Houston investigated a large American health record dataset (n=9,066) over the age of 60 years old. Findings showed that flu shots were correlated with a lower incidence of the disease. People who had gotten at least one flu vaccination were 17% less likely to receive a subsequent diagnosis of Alzheimer’s dementia, and those who got a more frequent flu vaccination were associated with another 13% reduction in Alzheimer’s

dementia incidence. The study also indicated those who received their first vaccine at a younger age had a stronger benefit than those who got it after 70 years old.

The second study, presented by researchers from the Duke University Social Science Research Institute, looked at the pneumococcal vaccine among 5,146 participants over the age of 65 years old from the Cardiovascular Health Study. The researchers found if the vaccination is given between age 65 and 75, there is a reduced risk of developing Alzheimer’s disease (AD) by 25-30% after adjusting for sex, race, birth cohort, education, smoking and genetic risk factors. A subset of this group - people who didn’t carry a specific allele in the TOMM40 gene (known as a genetic risk factor for AD) – was up to 40% less likely to develop the disease.

The third study aimed to investigate the association between several infections and the mortality in people with and without dementia. The study conducted at the Danish Dementia Research Centre, Rigshospitalet and the University of Copenhagen in Denmark used data from Danish national health registries. Scientists reported that people with dementia have a higher risk of dying after infections (6-fold) than those without dementia (3-fold).

https://www.alz.org/aaic/releases_2020/vaccines-dementia-risk.asp

29 July: US Alzheimer’s Association hosts a panel discussion on COVID-19 and Alzheimer’s disease



As it has spread across the globe, the COVID-19 pandemic has disrupted all aspects of life, from daily social interactions to large-scale clinical research studies. On 29 July, as part of its 2020 Annual Conference, the US

Alzheimer’s Association held a panel discussion aimed at shedding light on how AD communities have been affected by the COVID-19 crisis.

Attended by journalists from several high-profile media outlets, the panel discussion started with brief presentations from clinical research and policy experts, covering topics such as the impact of the pandemic on AD research trials, how COVID-19 affects the brain and cognition, and the devastating effects of COVID-19 on people with dementia in long-term care.

Professor Gregory Jicha, a neurologist from the Sanders-Brown Center on Aging in Kentucky, started by outlining how clinical trials such as the US POINTER and A4 studies have had to institute remote, at-home monitoring, which has reduced recruitment. However, he emphasised that there are tools available to enable participants to attend study visits in a safe and protected manner, such as COVID-19 testing, the use of PPE and physical distancing measures.

Professor Neelam Aggarwal of the Rush Alzheimer’s Disease Center then summarised our current understanding of how COVID-19 affects the brain and cognition. In particular, she

drew attention to the neurological symptoms of COVID-19 (loss of smell, increased risk of stroke) and gender-related differences in risk. She also emphasised that COVID-19 has amplified existing health disparities linked to ethnicity, social deprivation and age.

This theme was continued by Dr Maria Carillo and Beth Kallmeyer of the Alzheimer’s Association, who discussed how COVID-19 has exposed health differences that exist between different racial and ethnic groups. They emphasised that a disproportionate share of the COVID-19 burden is being borne by the most vulnerable populations, such as people with dementia in long-term care.

Consequently, the Alzheimer’s Association has issued 16 policy recommendations to improve governmental responses in the long-term care setting, on testing, COVID-19 case reporting, management of clusters and practical support measures.

For more information, please read the Alzheimer’s Association press release:

https://www.alz.org/aaic/releases_2020/covid-19-cognition-media-panel.asp

30 July: New research suggests that early-life health factors may influence Alzheimer’s dementia risk



Risk factors for Alzheimer’s dementia may be measurable in adolescents and young adults, according to three research studies presented at the Alzheimer’s Association International Conference (AAIC) on 30 July. These risk factors include health factors such as high blood pressure, high cholesterol and diabetes and social factors such as education quality.

The Study of Healthy Aging in African Americans (STAR) looked at 165 adolescents, 439 young adults and 110 adults. Kristen Georges from University of California Davis and his colleagues reported that hypertension, diabetes, or having two or more heart health risk factors at adolescence and adulthood were associated with statistically significantly worse late-life cognition. According to the researchers, these findings suggest

that cardiovascular disease risk factors as early as adolescence may influence late-life brain health in African Americans.

A second study analysed the impact of body mass index (BMI) at the age of 20 on the risk for later-life dementia in a total of 5,104 older adults. For women, dementia risk was 1.8 times higher among those who were overweight and 2.5 times higher among those who were obese compared to women with normal BMI in early life. For men, dementia risk was 2.5 times higher among those who were obese in early adulthood, 1.5 times higher among those who were overweight in mid-life and 2.0 times higher among those who were obese in mid-life. Adina Zeki Al Hazzouri from Columbia University and colleagues suggested that high BMI in adulthood is a risk factor for dementia in late life.

A study conducted by Justina Avila-Rieger from Columbia University Medical Center analysed the relationship between years of education and dementia risk on 2,446 participants enrolled in the Washington Heights/Inwood Columbia Aging Project (WHICAP), who attended elementary school in the US. The study tracked variables such as mandatory school enrolment age, minimum dropout age, school term length, student-teacher ratio and student attendance.

The analysis found that participants who attended school in states with lower quality education had more rapid decline in memory and language in later life. Higher quality of education was associated with lower risk of dementia for non-Hispanic white women, black men and women. These findings provide evidence that later life dementia risk and cognitive function is influenced by early-life state educational policies.

https://www.alz.org/aaic/releases_2020/early-life-risk-factors-dementia.asp

SCIENCE WATCH

1 July: Clinical study identifies novel biomarker for cognitive decline in late middle age



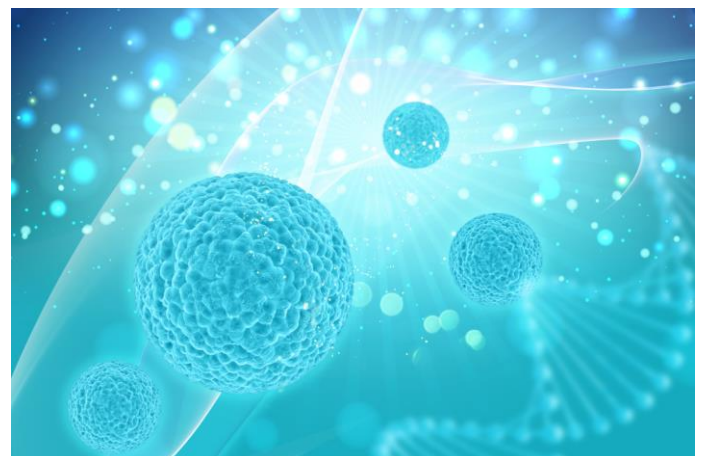
A team of researchers led by Dr Roy Soiza recently published an article describing a novel biomarker for cognitive decline in late middle age, based on analyses of the 1936 Aberdeen Birth Cohort study (ABC36).

The ABC36 study, which was initiated in 2000, recruited 506 Aberdonian participants born in 1936. Each participant had completed an assessment of cognitive performance in 1947, when they were 11, and following recruitment to the ABC study (at the age of 63) regularly underwent cognitive tests and biosampling procedures. The researchers focused on four years of follow-up, when participants were aged between 63 and 67 years – a period defined as ‘late middle age’.

In total, 93 participants contributed to the analyses performed by Dr Soiza and colleagues. After adjusting for potential confounders, including cognitive performance as a child, higher levels of plasma ADMA (asymmetric dimethylarginine) at baseline were associated with a more rapid decline in cognitive performance between the ages of 63 and 67. These results suggest that ADMA, an easily measurable risk marker for cardiovascular disease, may also be an early indicator of cognitive decline in older age.

<https://onlinelibrary.wiley.com/doi/full/10.1002/gps.5355>

1 July: Researchers at Lund University develop a new model for studying hippocampus dysfunction in AD



A team led by Dr Laurent Roybon at Lund University has recently published an article in Stem Cell Reports, outlining the development and validation of an innovative platform to study hippocampal dysfunction in Alzheimer’s disease (AD).

The hippocampus is one of the first regions in the brain to be affected during the development of AD, undergoing degenerative changes that lead to loss of memory. However, studying the molecular pathways that cause these changes in the hippocampus is complicated by limited tissue availability. A further problem is the fact that mouse models of AD do not always recapitulate the human disease. Induced pluripotent stem cells (iPSC), created using skin cells donated by people with AD, offer a potential solution to these problems, enabling researchers to study the molecular causes of AD in the human context.

In their paper, Dr Roybon and colleagues describe the methodology for creating 3D spheroids of hippocampal cells, using skin cells from two patients with different types of genetic AD as their starting material. This involved a form of

molecular time-travel, first turning back the clock to an early developmental stage (creating iPSC) then fast-forwarding them into hippocampal cells. These cells were grown in a 3D matrix, rapidly creating hippocampal spheroids from patients with AD.

A series of *in vivo* and *in vitro* tests showed that the hippocampal spheroids retained many of the features of AD, including increased ratios of pathogenic amyloid-beta proteins and the presence of synaptic pathology. Interestingly, the protein composition of the hippocampal spheroids differed according to the type of genetic AD of the original skin cell donor. Finally, the researchers were able to use gene therapy to alter the gene expression programme of the hippocampal spheroids, promoting the expression of genes involved in synaptic transmission.

[https://www.cell.com/stem-cell-reports/fulltext/S2213-6711\(20\)30192-2#%20](https://www.cell.com/stem-cell-reports/fulltext/S2213-6711(20)30192-2#%20)

1 July: BrainStorm Cell Therapeutics plans a new Phase II trial evaluating NurOwn for AD

BrainStorm Cell Therapeutics Inc., a leading developer of adult stem cell therapies for neurodegenerative diseases, has announced a new clinical Phase II trial for Alzheimer’s disease (AD). The company plans to conduct a 52-week, open-label and proof-of-concept trial to evaluate the safety and efficacy of NurOwn in people with prodromal to mild AD.

The clinical trial will be conducted in several clinical trial sites in the Netherlands and France. 40 participants will receive three doses of NurOwn during 8 weeks. The company reported that the protocol has been submitted for EU regulatory approval.

NurOwn is a cell therapy that uses mesenchymal stem cells. These cells have the capacity to generate different cell types. BrainStorm has completed several clinical trials evaluating NurOwn and has recently fully enrolled a Phase III trial with NurOwn for the treatment of amyotrophic lateral sclerosis (ALS). BrainStorm also recently received acceptance from the US Food and Drug Administration (FDA) to initiate a Phase II open-label multicentre trial in progressive multiple sclerosis.

7 July: Annovis Bio receives institutional review board approval to launch a Phase II study with ANVS401 in Alzheimer’s and Parkinson’s disease



On 7 July, Annovis Bio, a clinical-stage drug platform company developing novel treatments for neurodegenerative diseases such as Alzheimer’s disease (AD)

and Parkinson’s disease (PD), announced that it has received Central Institutional Review Board (IRB) approval to initiate a

new Phase II clinical study investigating its lead compound ANVS401 in AD and PD.

ANVS401 is a small orally administered brain penetrant inhibitor of neurotoxic proteins. The purpose of the IRB is to assure that appropriate steps are taken to protect the rights and welfare of participants in a research study.

The company is expecting to enrol 68 research participants with early AD and early PD at 15 sites across the US. They will receive ANVS401 for one month.

<https://bit.ly/2Elu9IC>

7 July: TouchNeurology article discusses the prevention of dementia in diabetes



The TouchNeurology website has published an Insight article by Dr Sanjay Kalra and colleagues, outlining the links between dementia and type 2 diabetes, and identifying clinical strategies for the prevention of dementia in people with diabetes. TouchNeurology is an independent information resource supporting physicians, clinicians and Industry professionals, publishing free-to-access articles aimed at the neurology community.

In their article, Dr Kalra and his colleagues describe the results of several cross-sectional and longitudinal studies, highlighting figures that show people with type 2 diabetes have a 60% increased risk of developing dementia. Cross-sectional studies indicate that women with diabetes are at particularly high risk of developing vascular dementia, while men and women with diabetes have similar risk levels for developing non-vascular dementia (49% and 53%, respectively). Longitudinal studies, meanwhile, show that people with type 2 diabetes develop dementia 1.7 years earlier than their non-diabetic counterparts.

With those figures in mind, Dr Kalra and colleagues suggest several strategies for preventing dementia in diabetes. These include optimising glycaemic control for people with diabetes, improved management of associated conditions such as hypertension and obesity, and recommendations for increased physical activity. Secondary prevention measures include screening for cognitive impairment in older people with diabetes, with regular monitoring for those experiencing

cognitive impairment. They also suggest that carers should be supported to avoid physical and emotional fatigue, and that therapeutic regimens should be carefully chosen to facilitate adherence. Finally, Dr Kalra and colleagues call for increased awareness of diabetes dementia among healthcare professionals, policymakers and the general public.

<https://touchneurology.com/insight/prevention-of-diabetes-dementia/>

7 July: Clinical study identifies link between sensory impairments and dementia



On 7 July, Dr Philip Hwang and colleagues published an article in *Alzheimer's & Dementia: Diagnosis, Assessment and Disease Monitoring*, indicating that people with hearing and visual

impairments may be at higher risk of developing dementia.

Similar to dementia, the incidence of sensory impairments such as hearing loss and poor eyesight increases with age, with a 2004 EU cross-sectional study showing that over 13% of participants aged over 50 experienced hearing difficulties. The same study found that almost 6% of the 27,536 people analysed had dual sensory impairments (both hearing loss and poor eyesight), rising to 15% of individuals aged over 80 years in a US community-based study.

To assess whether there is an association between late-life hearing and visual impairments and dementia, Dr Hwang and colleagues analysed data from the Ginkgo Evaluation of Memory (GEM) study, a randomized-controlled trial aiming to determine the efficacy of *ginkgo biloba* in the prevention of dementia. The GEM study enrolled over 3000 healthy participants aged 75 years and over, following them up every 6 months for a period of 6-8 years. Throughout the study, participants self-reported whether they had any hearing or visual impairments; 15.6% of participants developed dementia during the course of the study. Analysing data from 2051 GEM participants, the researchers found that having both visual and hearing impairment was associated with an 86% higher risk of developing dementia and 112% increased risk of Alzheimer's disease. Visual impairment alone was also associated with an increased risk of dementia (32%). However, further studies are required to establish whether there is a causal relationship between sensory impairment and dementia.

<https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/dad2.12054>

8 July: Biogen files for FDA license for aducanumab

On 8 July, the biotechnology company Biogen completed the submission of a biologics license application to the US Food and Drug Administration (FDA) for aducanumab as a treatment for Alzheimer's disease (AD). The data underpinning the filing

came from the phase III EMERGE and ENGAGE studies, as well as the Phase Ib PRIME study.

In October 2019, the company announced that the Phase III EMERGE trial met its primary endpoint, showing a significant reduction in clinical decline. The investigational drug was tested in people with mild cognitive impairment due to AD and mild AD dementia. However, the Phase III ENGAGE study did not meet its primary endpoint with the same participant group.

The aducanumab clinical programme also included the results of the Phase Ib PRIME study and its long-term extension in people with early AD. Findings showed that aducanumab reduced amyloid beta plaques in a dose- and time-dependent manner and reduced clinical decline.

Biogen requested a priority, six-month review. The company is continuing to engage dialogue with regulatory authorities in Europe and Japan.

<https://bit.ly/2FYncIO>

The FDA has since responded - see p. 25 for details.

11 July: Apathy, but not depression, may predict dementia in people with small vessel disease



Narrowing of the small blood vessels in the brain, also known as cerebral small vessel disease (SVD), is one of the leading causes of dementia, due to the damage this causes in areas of the brain associated with cognition. Apathy, defined as a reduction in goal-directed behaviour, is a common neuropsychiatric symptom of SVD, but is sometimes confused with depression, partly because the clinical scales used to measure apathy and depression overlap in content.

In their research study, published in the *Journal of Neurology, Neurosurgery & Psychiatry* on 11 July, Dr Jonathan Tay and colleagues aimed to determine whether apathy or depression were predictors of dementia in people with SVD. Using two prospective cohort studies of SVD (the St. Georges Cognition and Neuroimaging in Stroke study/SCANS and the Radboud University Nijmegen Diffusion Tensor and Magnetic Resonance Cohort study/RUN DMC) they analysed baseline brain imaging and cognitive test scores for over 450 participants. Depression and apathy was assessed using specific neuropsychiatric

questionnaires. The researchers also analysed longitudinal data from 104 SCANS study participants to evaluate whether depression or apathy could predict the development of dementia over time.

While there were some differences in the incidence of dementia between the two cohorts (19.8% and 10.8% of SCANS and RUN DMC participants, respectively), Dr Tay and colleagues found that individuals with higher apathy scores at baseline across both cohorts had a greater risk of developing dementia. Longitudinal data from SCANS showed that increasing apathy was associated with a 53% increased likelihood of dementia. In contrast, depression did not predict dementia in either cohort, suggesting that apathy, but not depression, may be a prodromal symptom of dementia in people with SVD.

<https://jnp.bmj.com/content/early/2020/07/10/jnp-2020-323092>

14 July: The Alzheimer's Clinical Trials Consortium initiates a Phase III clinical trial of BAN2401 for preclinical Alzheimer's disease

The Alzheimer's Clinical Trials Consortium (ACTC), established by the National Institute on Aging at the National Institutes of Health, is a clinical trials infrastructure designed to accelerate and expand studies for therapies in Alzheimer's disease (AD) and related dementias.

On 14 July, ACTC, Eisai and Biogen announced that a new Phase III clinical trial has been initiated in the US to evaluate the efficacy and safety of BAN2401, an anti-amyloid beta protofibril antibody, in people with preclinical AD. The AHEAD 3-45 Phase III clinical program includes two trials: The A45 trial and the A3 trial and will be conducted in the US, Japan, Canada, Australia, Singapore, and Europe. A total of 1,400 research participants will receive BAN2401 or placebo for 216 weeks. The A45 trial will enrol cognitively normal participants who have elevated levels of amyloid in the brain and the A3 trial will enrol cognitively unimpaired participants who have an intermediate amount of amyloid in the brain. The design of this new Phase III clinical trial was presented at the Alzheimer's Association International Conference (AAIC) from 27 to 31 July 2020.

In addition, Eisai presented the latest data from its Phase IIb open-label extension study of BAN2401 in early AD at AAIC. The preliminary findings showed a rapid decrease in amyloid levels in the brain after three months of treatment with BAN2401.

<https://www.eisai.com/news/2020/news202042.html>

20 July: FDA accepts application for pimavanserin for the treatment of hallucinations and delusions associated with dementia-related psychosis

On 20 July, ACADIA Pharmaceuticals Inc. announced that the US Food and Drug Administration (FDA) has accepted for filing its supplemental New Drug Application for pimavanserin for

the treatment of hallucinations and delusions associated with dementia-related psychosis. The application was accepted by FDA with a decision set for April 2021

This application is supported by findings from the HARMONY Phase III trial, which evaluated the safety and efficacy of pimavanserin for the treatment of hallucinations and delusions associated with Lewy Bodies, vascular dementia and frontotemporal dementia.

The study met its primary endpoint, demonstrating that pimavanserin significantly reduced the risk of relapse of psychosis by 2.8 fold compared to placebo. Pimavanserin is an antipsychotic drug that is currently approved for Parkinson's disease-related psychosis, under the trade name NUPLAZID. Pimavanserin functions by blocking the 5HT_{2a} serotonin receptor and is classified as a selective serotonin inverse agonist.

<https://bit.ly/2G3PAy1>

27 July: Primary results of the AMBAR trial show that plasma exchange with albumin treatment may slow cognitive decline in AD

On 27 July, Mercè Boada and coinvestigators published primary results from the AMBAR study in the Alzheimer's and Dementia journal, showing some cognitive and functional benefit of albumin replacement therapy in Alzheimer's disease (AD). Albumin replacement therapy involves the intravenous extraction of blood plasma and the infusion of an albumin solution, in a process known as 'plasma exchange' or PE. The AMBAR study was based on the hypothesis that PE and albumin replacement therapy could help reduce levels of amyloid beta proteins, thanks to the ability of plasma albumin to bind and sequester this harmful protein.

The AMBAR (Alzheimer Management By Albumin Replacement) study was a phase 2b/3 randomised, placebo-controlled clinical trial, enrolling participants with mild to moderate AD in Spain and in the US. Initiated in 2011, AMBAR screened 496 people with mild/moderate AD, randomising 347 participants to one of four treatment arms: three arms with plasma exchange and albumin replacement at increasing doses, and one sham or placebo arm. AMBAR participants received weekly PE for a 6-week period, followed by a year of monthly infusions.

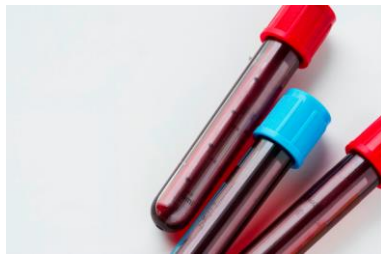
The co-primary outcomes of AMBAR were functional and cognitive status at 14 months, as measured by the ADCS-ADL and ADAS-Cog neuropsychological tests. Analyses showed a significant reduction in functional and cognitive decline in participants receiving PE, with 52% and 66% reductions in



decline. Subgroup analysis revealed some differences in the scale of treatment benefit between participants based on their AD severity at baseline: in particular, participants with moderate AD experienced greater improvements in cognitive status on the ADAS-Cog scales compared to those with mild AD.

<https://bit.ly/2EF4MkN>

28 July: Clinical study confirms the diagnostic accuracy of blood test for p-tau217 biomarker in AD



The accumulation of disordered, phosphorylated tau proteins in the brain is a defining neuropathological feature of Alzheimer’s disease (AD). Currently,

tests to assess tau in the clinic are limited to PET scans or cerebrospinal fluid (CSF) analyses, which involve invasive and costly lumbar punctures. To meet the need for minimally-invasive and rapid tests for tau in people with suspected AD, several groups have developed plasma assays for blood-based biomarkers, including phosphorylated forms of the tau protein such as p-tau181 and p-tau217.

In their research study, published in the Journal of the American Medical Association on 28 July, Dr Sebastian Palmqvist and colleagues set out to establish whether a blood plasma test for p-tau217 could accurately differentiate AD from other neurodegenerative disorders. They also sought to compare the p-tau217 test to plasma, CSF and brain imaging tests for other AD-associated proteins such as p-tau181, neurofilament light chain (NfL) and beta-amyloid. To do this, they assessed biosamples and scans from participants in three separate cohorts: An Arizona-based Neuropathology Cohort, the Swedish BioFINDER-2 Study, and the Colombian Autosomal Dominant AD Registry.

In total, 1402 participants were included in the researchers’ analyses, which showed that a plasma p-tau217 test could accurately distinguish people with clinically diagnosed AD dementia from those with other neurodegenerative disorders. In addition, levels of plasma p-tau217 were strongly correlated to the amount of tangled tau detected on PET scans of the brain, and were elevated early in the AD disease process. In comparison to plasma p-tau181, plasma NfL and MRI imaging, plasma p-tau217 had a higher clinical diagnostic accuracy, and performed similarly well to CSF measures of AD pathology.

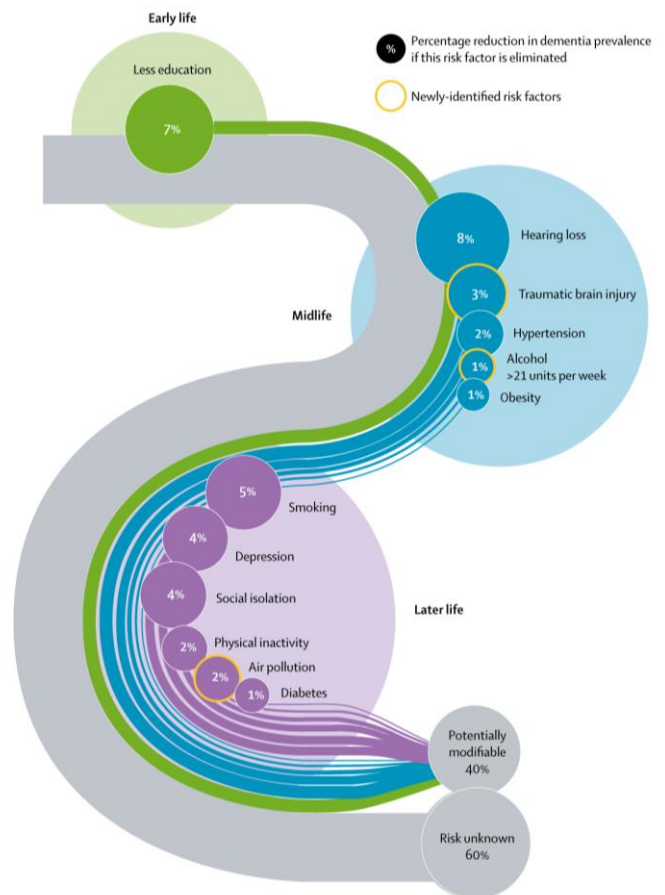
Together, these results add to a substantial body of work in clinical study participants confirming the utility of minimally-invasive blood tests for tau as a diagnostic or monitoring tool for AD. Further studies are now required in larger, unselected – and more ethnically diverse – primary care populations.

<https://jamanetwork.com/journals/jama/fullarticle/2768841>

30 July: Lancet Commission on dementia prevention, intervention and care identifies 12 modifiable risk factors accounting for 40% of dementias

Risk factors for dementia

An update to the Lancet Commission on Dementia prevention, intervention, and care presents a life-course model showing that 12 potentially modifiable risk factors account for around 40% of worldwide dementias



In the 2019 Alzheimer Europe Yearbook on the prevalence of dementia, we estimated that the number of people with dementia in Europe would double by 2050, to over 14 million in the European Union alone. Published on 30 July, the 2020 Lancet Commission on dementia prevention, intervention and care identifies twelve modifiable risk factors that may account for 40% of these cases. Theoretically, modification of these risk factors could prevent or delay the development of dementia, particularly in low- and middle-income countries where more dementias occur and where risk factor prevalence is higher.

The 2017 Lancet Commission on dementia prevention, intervention and care identified nine modifiable risk factors associated with increased dementia prevalence: less education, hypertension, hearing impairment, smoking, depression, obesity, diabetes, physical inactivity and low social contact. In their 2020 update to the Commission report, Professor Gill Livingston and co-authors have added three more modifiable risk factors to this list: excessive alcohol consumption, traumatic brain injury and air pollution.

disease (AD) and would also be the first therapy to demonstrate that removing amyloid beta resulted in better clinical outcomes.

Nearly one month after completed the submission of its license application for its investigational drug aducanumab, Biogen has received the acceptance of its licence application. The data underpinning the filing come from the phase III EMERGE and ENGAGE studies as well as the Phase Ib PRIME study.

<https://bit.ly/34IGdhp>

18 August: Study looks at person-centred approach to implementation of psychosocial interventions for people with an intellectual disability and dementia



A research team, based at the University of Stirling in Scotland, has completed a participatory action study assessing a person-centred approach to implementation of psychosocial interventions with people who have an intellectual disability and dementia. The study results were published in the Journal of Applied Research in Intellectual Disabilities

(JARID), on 18 August 2020. There is a link to an accessible summary included in the published study.

Dementia disproportionality affects people with Down syndrome at an earlier age, on average 55 years, and is associated with mortality in 70% of adults. People with intellectual disabilities other than Down syndrome are also more likely to develop dementia earlier, on average 10 years prior to that experienced by the population without an intellectual disability.

The number of people with an intellectual disability and dementia presents a global health and social challenge with an associated need to reduce stress or agitation and improve quality of life in affected individuals. On this premise, the study aimed to establish the effectiveness of psychosocial interventions in social care settings and to explore the use of photovoice methodology to develop dialogue about dementia. Photovoice is a qualitative method used in community-based participatory research to document and reflect reality.

This mixed-method participatory action study used individualised goal-setting theory with 16 participants with intellectual disability and dementia, and 22 social care staff across 11 sites. Five co-researchers with intellectual disability were part of an inclusive research team collecting data using existing and bespoke tools including photovoice.

Goals typically related to improving mood; a desire to reduce anxiety, confusion and agitation; wanting to feel “more like myself”; engagement in new or previously enjoyed activities; and personal safety. Relevant psychosocial interventions to meet these goals were chosen by participants based on their own needs and preferences.

74% of individual goals met or exceeded expectations with reduction in some “as required” medication. Qualitative findings include themes of enabling care and interventions as tools for practice. Photovoice provided insight into previously unreported fears about dementia.

The study, which was funded by Alzheimer’s Society and is available in open access, concluded that individualised psychosocial interventions have the potential to reduce distress or agitation in people with an intellectual disability and dementia.

<https://onlinelibrary.wiley.com/doi/10.1111/jar.12795>



DEMENTIA IN SOCIETY

3 August: Nobel Peace Prize winner John Hume dies with dementia

The Nobel Peace Prize winner and prominent Northern Ireland politician John Hume has died, aged 83, with dementia.

He was a founding member of the Social Democratic and Labour Party (SDLP) in 1970 and led the party from 1979 until 2001. He also served as Member of the European Parliament (MEP) for more than 25 years.



One of the highest-profile politicians in Northern Ireland for more than 30 years, he took considerable risks for peace in the late 1980s, by holding talks with the then leader of Sinn Féin, Gerry Adams. The Hume-Adams talks helped to lay the foundations for the 1994 IRA ceasefire and later negotiations which resulted in the Good Friday Agreement. Mr Hume played a major role in bringing about the Good Friday Agreement in 1998, effectively putting an end to the “Troubles”.

Following the 1998 peace deal, Mr Hume was awarded the Nobel Peace Prize, along with the then leader of the Ulster Unionist Party, David Trimble.

10 August: Are you a patient at a memory clinic, a carer or a physician? Take this brief survey on computer tools in dementia diagnostics



A new project run by the Alzheimer Center Amsterdam aims to further develop and

implement a number of computer programmes (also referred to as “computer tools”) that can be used in the memory clinic. These tools will, for example, support physicians in the diagnosis of dementia, as well as predicting what clinic patients can expect in the future.

In the further development and implementation of such tools it is very important to have feedback from physicians, memory clinic patients and their carers. The current study aims to collect valuable input from these groups, to be able to develop tools that truly meet their preferences and needs. This will also help to facilitate the successful implementation of these tools in memory clinic practice.

The project team has created two brief online surveys, consisting of a number of questions regarding “the sense/nonsense of computer tools in dementia diagnostics”. One is for memory clinic patients and carers, the other is for physicians working in memory clinics. Alzheimer Center Amsterdam would be most grateful for your help, if you can spare a few minutes of your time to respond.

The survey for patients/carers can be found at:

<https://vumc.datacoll.nl/PatientsurveyAlzheimerEurope>

The survey for physicians can be found at:

<https://vumc.datacoll.nl/physiciansurveyAlzheimerEurope>

These surveys are in English. Please contact Dr Aniek van Gils a.vangils@amsterdamumc.nl, if you would share the survey among your network in your own language, or if you need further information about the surveys or the project.

NEW PUBLICATIONS & RESOURCES

9 July: Collection of 22 short films produced by people living with dementia

People with dementia from groups across the UK have worked together to create a powerful and moving suite of short films. With funding from The National Lottery Community Fund, the largest funder of community activity in the UK, the people with dementia in these films are not just the subjects of the camera’s gaze, but its authors.

A thread running through many of the films is the power of peer support. All of the groups involved are members of a network of groups of people with dementia called DEEP. Their stories are all different, with dementia in the foreground and background, sometimes at the same time.



View the films, here:

<https://www.dementivoices.org.uk/deepmoments/>

Read more about the films, here:

<http://www.innovationsindementia.org.uk/news/>

24 July: Alzheimer Europe contributes to newly-published JPND paper “Measuring the well-being of people with dementia: a conceptual scoping review”

On 24 July, “Measuring the well-being of people with dementia: a conceptual scoping review” was published in online open access medical journal “Health and Quality of Life Outcomes”. The review was authored by the EU Joint Programme – Neurodegenerative Disease Research (JPND). Contributors include Alzheimer Europe Director for Projects Dianne Gove and Project Officer Ana Diaz.



Enabling people with dementia to “live well” is a policy and research priority in many countries. However, instruments for measuring outcomes of psychosocial interventions designed to promote well-being in dementia are often derived from a symptom-focused, loss/deficit approach, or from broad quality of life concepts. Research on the development of an alternative asset/strengths-based conceptual framework of well-being in dementia was needed, said the authors. Their paper takes forward this recommendation by developing such a framework and using this to map relevant self-report outcome measures. You can access the article, here:

<https://hqlo.biomedcentral.com/articles/10.1186/s12955-020-01440-x>

26 July: European Academy of Neurology publishes guideline on medical management issues in dementia, co-authored by Alzheimer Europe

On 26 July, “A European Academy of Neurology guideline on medical management issues in dementia” was published (early view) in the European Journal of Neurology. It was co-authored by Jean Georges, Executive Director of Alzheimer Europe. The guideline addresses



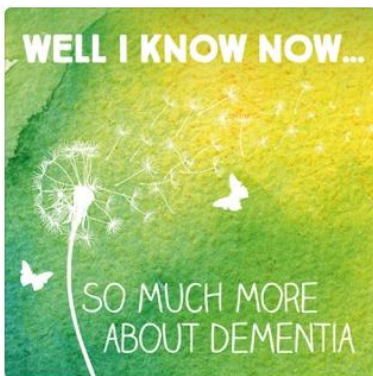
important medical management issues in dementia including systematic medical follow-up, vascular risk factors, pain, use of antipsychotics, and epilepsy. You can access the article, here:

<http://dx.doi.org/10.1111/ene.14412>

An interview with first author Kristian Steen Frederiksen has also been published, in which Dr Frederiksen introduces the guideline:

<https://vimeo.com/434807072>

28 July: “Well I know now” podcast series on dementia experiences is available online



“Well I Know Now” is a series of podcasts in which award-winning blogger Pippa Kelly and her guests discuss what their dementia experiences have taught them.

The series of eight podcasts, published between 8 June and 28 July 2020, includes a

conversation with Chris Roberts, Vice-Chairperson of the European Working Group of People with Dementia (EWGPWD) and his wife and carer Jayne Goodrick (episode 2), who are both strong advocates in the field of dementia. Other guests in the series include celebrated English cartoonist Tony Husband and Scottish broadcaster and writer Sally Magnusson, whose 2014 book “Where Memories Go” was written about her mother’s dementia. You can find the “Well I Know Now” series of podcasts, here:

<https://podcasts.apple.com/gb/podcast/well-i-know-now/id1513600445>

24 August: A new training course on patient engagement is available for industry professionals

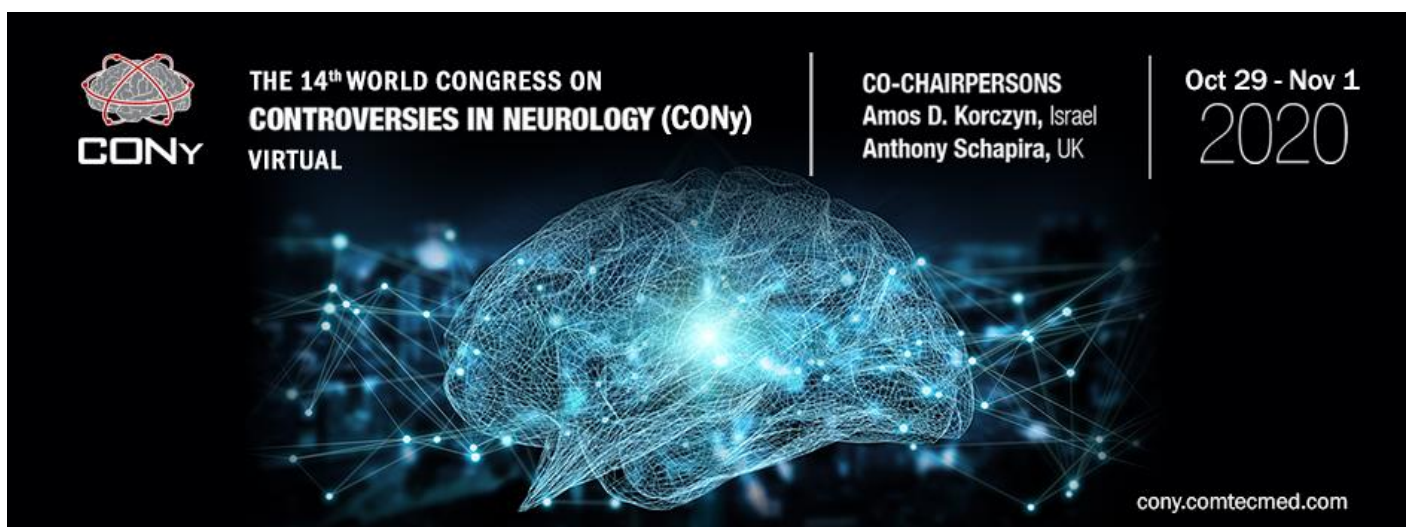
A new training course called “Patient Engagement Training for Industry Professionals” is available, from Patient Focused Medicines Development (PFMD). The course is a direct response to the industry’s demand in this often confusing and fragmented area. This learning programme aims to help those working within pharmaceutical or medical device organisations begin their patient engagement journey or else take it to the next level.

Two modules are available. The first module provides an introduction to patient engagement and aims to help participants support a culture shift, enabling systematic patient engagement, as well as helping to increase the adoption of patient engagement practices across the various teams within pharmaceutical companies. The second module bridges the gap between theory and practice. It provides the tools to operationalise the patient engagement fundamentals in day-to-day work.

While there may be an appetite for meaningful patient engagement, it requires the proper tools and methods and PFMD believes this new training course can help participants to understand the industry standards in this dynamic and evolving field. The training has been developed by PFMD *for* industry, *with* industry, patients and other stakeholders, in the spirit of co-creation and collaboration. The training integrates a variety of materials from different sources, and takes into account the need to keep patient capacity building a priority, with a built-in system to fund further patient training.

To find out more and to register for the course, go to:

www.learning.pfmd.org



CONy THE 14th WORLD CONGRESS ON CONTROVERSIES IN NEUROLOGY (CONy) VIRTUAL

CO-CHAIRPERSONS
Amos D. Korczyn, Israel
Anthony Schapira, UK

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2020

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Contact Alzheimer Europe:

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

Alzheimer Europe Board:

Chairperson: Iva Holmerová (Czech Republic); **Vice-Chairperson:** Charles Scerri (Malta); **Honorary Secretary:** James Pearson (UK, Scotland); **Honorary Treasurer:** Maria do Rósario Zincke dos Reis (Portugal). **Members:** Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (Ireland), Stefanie Becker (Switzerland), Marco Blom (Netherlands), Sabine Jansen (Germany), Pat McLoughlin (Ireland), Sirpa Pietikäinen (Finland), Jesús Rodrigo (Spain), Karin Westerlund (Sweden).

Alzheimer Europe Staff:

Executive Director: Jean Georges; **Communications Officer:** Kate Boor Ellis; **Conference and Event Coordinator:** Gwladys Guillory; **Director for Projects:** Dianne Gove; **Project Officers:** Cindy Birck, Angela Bradshaw, Ana Diaz; **Policy Officer:** Owen Miller; **Finance Officer:** Stefanie Peulen; **Administrative Assistant:** Grazia Tomasini.

AE CALENDAR

Date	Meeting	AE representative
7 September	Neuronet Communications Experts' Community meeting	Angela and Cindy
9 September	Informative meeting RADAR-AD Patient Advisory Board	Dianne and Ana
10 September	Information meeting with TauRx	AE members and staff
10 September	Dementia Panel of European Academy of Neurology	Jean
10 September	PARADIGM online Patient Engagement Open Forum	Ana
11 September	WW Fingers Network	Jean
18 September	VirtualBrainCloud GDPR meeting	Angela
22 September	Patients and Consumers Working Party of European Medicines Agency	Jean
28 September	Addressing dementia within migrant communities – EPC/EFID meeting	Owen and Dianne
29 September	Meeting of Neuronet Working Group on Data Sharing	Angela and Cindy
29 September	Meeting EWGPWD on the topic of Advance Care Planning	Dianne and Ana
30 September	Alzheimer Europe Board	AE Board
30 September	EPAD General Assembly meeting	Jean and Cindy

CONFERENCES

Date	Meeting	Place
5-6 October	21 st International Conference on Alzheimer's Drug Discovery https://meetings.alzdiscovery.org/alz-home/	Virtual Conference
20-22 October	30 th Alzheimer Europe Conference "Dementia in a changing world"	Virtual Conference
29 October – 1 November	The 14 th World Congress on controversies in neurology, http://cony.comtecmed.com/	Virtual Conference
4-7 November	13 th Clinical Trials on Alzheimer's Disease (CTAD) https://www.ctad-alzheimer.com/	Boston, US
16-18 November	2 nd Krems Dementia Conference, www.donau-uni.ac.at/dementia-conference	Krems, Austria
10-12 December	34 th International Conference of ADI "Hope in the age of dementia", https://adi2020.org/	Virtual Conference
18-21 February 2021	12 th Panhellenic Conference of Alzheimer's Disease (PICAD) and the 4 th Mediterranean Conference on Neurodegenerative Diseases (MeCoND), www.alzheimer-conference.gr	Thessaloniki, Greece
9-14 March 2021	AD/PD 2021 - The 15 th International Conference on Alzheimer's & Parkinson's Diseases, https://aat-adpd.kenes.com/	Barcelona, Spain
26-29 June 2021	Brain & Brain PET 2021, http://brain2021.scot/	Glasgow, UK
29 Nov - 1 Dec 2021	31 st Alzheimer Europe Conference	Bucharest, Romania

30th Alzheimer Europe Conference

Dementia in a changing world

Virtual Conference

20–22 October 2020

www.alzheimer-europe.org/conferences

 #30AEC

