European Alzheimer’s Alliance
Members share their views on key EU policy areas for the year ahead

Lenny Shallcross
The Executive Director of the World Dementia Council speaks about their Dementia Landscape Project

Marjolein de Vugt
Is the new Chairperson of the Interdem network of researchers

Stefan Eriksson
Is living (and hiking) with dementia, with support from his daughter Janni
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Welcome

It is a great pleasure to introduce the 38th edition of our Dementia in Europe magazine. As ever, we have done our best to fill it with interesting and useful updates on European and national policy developments in the dementia field, campaigns and European research projects, among others.

The first section of the magazine looks at some of the key work our organisation has been involved in, in recent months. The opening article recounts the European Parliament Workshop held online in December 2021, which looked at the new Innovative Health Initiative (IHI) and how it will build on the success of the Innovative Medicines Initiative (IMI).

We then introduce a new European project, the European Platform for Neurodegenerative Diseases (EPND), and two new Alzheimer Europe publications for 2021, our Yearbook on dementia-inclusive initiatives and communities and our ethics report on sex, gender and sexuality in the context of dementia. These topics were also explored at two recent sessions of our ever-popular Alzheimer’s Association Academy series. In the last article in this section, we share details of these two Academy sessions, both of which took place online.

In the Policy Watch section, we hear first from seven MEPs, all of whom are members of the European Alzheimer’s Alliance, setting out their views on where dementia policy is heading at an EU level in the year ahead and how they will promote it in their role. We also share details of the European Group of Governmental experts on dementia, whose final meeting of 2021, featured presentations from the Global Coalition on Aging (GCOA) and the World Health Organization (WHO) were also present. The WHO’s newly-launched Pan-European Mental Health Coalition is the topic of our next article, while the penultimate one takes on a more global flavour, focusing on the World Dementia Council’s series of “Global Dialogues” held throughout 2021.

This section closes with a contribution from our Finnish member, Muistiliitto – The Alzheimer Society of Finland, about their recently-published report highlighting the growing number of people with memory disorders and the corresponding increase in the financial impact on Finnish society.

The Dementia in Society section opens with two interview pieces, with people working in the field of dementia research and care in Europe. The first interview is with outgoing INTERDEM Chairperson Myrra Vernooij Dassen and her successor Marjolein de Vugt, while the next is with Sabine Jansen, who has stepped down from her position as Executive Director of the German Alzheimer association. We also hear from her successor, Saskia Weiss. In the next article, another of our members associations, Alzheimer Portugal, shares details about a recent study on “The cost and burden of Alzheimer’s disease in Portugal” and explores some of the key findings.

In the Policy Watch section, we hear first from seven MEPs, all of whom are members of the European Alzheimer’s Alliance, setting out their views on where dementia policy is heading at an EU level in the year ahead and how they will promote it in their role. We also share details of the European Group of Governmental experts on dementia, whose final meeting of 2021, featured presentations from the Global Coalition on Aging (GCOA) and the World Health Organization (WHO) were also present. The WHO’s newly-launched Pan-European Mental Health Coalition is the topic of our next article, while the penultimate one takes on a more global flavour, focusing on the World Dementia Council’s series of “Global Dialogues” held throughout 2021.

The Davos Alzheimer’s Collaborative, which has been in action for just over a year, aims at mounting a global response to Alzheimer’s. Founding Secretary Drew Holzapfel speaks to us about this initiative, and what it has achieved so far, while the next article in this section takes a rather different turn, exploring ageing and dementia-friendly urban design. Edition 7 of the Journal of Urban Design and Mental Health saw guest editors Daniel Gan and Zdravko Trivic focusing on this topic and they both provide comments, as does Helga Rohra, author of one of the papers included in the journal.

The last article in this section is a piece about the Forget Me Nots, a dementia-inclusive community choir in Ireland, that delegates had the pleasure of hearing at the closing ceremony of the 31st Alzheimer Europe Conference (31AEC).

The conference itself is the focus of the fourth and final section of the magazine, “Spotlight on 31AEC”. The event, which was virtual for the second year in a row due to the pandemic, was co-moderated by Kim Coppes from Live Online Events and Jean Georges, Executive Director of Alzheimer Europe. It was a great success, with well over 600 participants, from 42 countries, as well as 260 speakers and 100 poster presentations. In this section, we revisit some of the key presentations, and special sessions. We also summarise the symposia held during the event, including the ever-popular EWGPWD session.

I hope you enjoy our magazine, and as we head into 2022, I wish you all a safe and prosperous year!

Iva Holmerová, Chairperson
Alzheimer Europe hosts online European Parliament Workshop

Alzheimer Europe hosted an online European Parliament Workshop, “The Innovative Health Initiative: Building on the success of the Innovative Medicines Initiative”, examining the benefits of the approach of the Innovative Medicines Initiative (IMI) research partnership, as well as exploring the potential of the successor partnership, the Innovative Health Initiative (IHI).

On 28 September, Alzheimer Europe hosted an online European Parliament Workshop with Neuronet, entitled “The Innovative Health Initiative: Building on the success of the Innovative Medicines Initiative” looking at the future public-private partnership between the EU and industry partners. Alzheimer Europe Chairperson Iva Holmerová chaired the event, which was attended by 65 people, including EU policymakers, representatives from national Alzheimer’s associations, national health ministries, pharmaceutical companies, researchers and members of the European Working Group of People with Dementia.

Pierre Meulien, Executive Director, Innovative Medicines Initiative (IMI), outlined the success of IMI-funded research projects focused on dementia. He explained that the public-private partnership model had been of value for dementia and other neurodegenerative diseases, due to the complexity of the conditions and the high drug attrition rates. Over EUR 315 million has been invested in research into brain disorders by IMI, including projects which had changed the understanding of Alzheimer’s disease, as well as creating resources and infrastructure to facilitate future research in the field. The collaborative nature of the projects in IMI was identified as a particular strength of the approach, including the involvement of patient organisations such as Alzheimer Europe. Looking to the future, the importance of enabling technologies at a pre-competitive phase and pan-European consortia were singled out as key elements collaborations under the Innovative Health Initiative (IHI).

Carlos Díaz, Neuronet project leader, Synapse, presented on lessons learned from IMI-funded projects and how the work of Neuronet, which includes 20 different IMI neurodegeneration projects, was working to find synergies across the neurodegeneration portfolio. He highlighted Neuronet’s work to date, including its Knowledge Base, a dashboard which allows people to more easily search IMI neurodegenerative projects, their deliverables and tools. In addition, the creation of an asset map and network diagrams have allowed for visual representations of the gaps. Challenges associated with existing funding mechanisms were highlighted, including the sustainability of activities beyond the life of projects, as well as a perceived disconnect between decision-makers and principal investigators. As such, he argued that there is a need for a systems leadership approach to these types of projects.

Nicolas Creff, Senior Manager Research Partnerships, Science Policy & Regulatory Affairs, European Federation of Pharmaceutical Industries and Associations (EFPIA), presented on the forthcoming IHI, outlining the new collaboration between both pharmaceutical and pharma technology partners and highlighting that the new focus for the partnership will increasingly be on cross sector opportunities which make better use of data, drugs and medical devices. Furthermore, there will be a move towards broader themes of public health priorities, rather than specific diseases areas, however, there will be a consideration of aspects such as the prevalence of disease, high economic impacts and the transformational potential of research. It is expected that the legislative basis for the partnership should be completed by the end of the year, with calls potentially being issued as early as the first quarter of 2022.

Susan Wille Schwarz, Director of Communications, Global Coalition on Aging, presented the Alzheimer’s Innovation Readiness Index, which was jointly written with Alzheimer’s Disease International. The report compares 10 European countries across five different domains: strategy and commitment; early diagnosis and detection; access to care; awareness and monitoring and; care standards and settings. The report demonstrates that whilst there is some progress in countries, there remains significant variation across Europe, with many long-standing issues related to diagnosis, access to care and provision of adequate resources and funding, meaning that there are still significant difficulties for people with dementia and their carers across Europe.

Concluding the Workshop, Iva Holmerová thanked presenters and participants for their contributions and expressed hope that the next Workshop would be in person.

Videos from the event can be viewed at: http://bit.ly/AlzheimerEurope_YouTube
EPND: accelerating the discovery of biomarkers for neurodegenerative diseases

Alzheimer Europe is part of the newly-launched Innovative Medicines Initiative (IMI) project, EPND (European Platform for Neurodegenerative Diseases). In this article, the project leaders discuss the aims and aspirations of the new initiative.

Unprecedented volumes of data and samples are being generated each day by clinical research projects on neurodegenerative disorders such as Alzheimer’s and Parkinson’s disease. These valuable resources hold the key to new diagnostics and treatments, with the potential to identify genetic risk factors, biomarkers, and novel drug targets for progressive diseases that are currently incurable.

Biomarkers have an important role to play in facilitating early diagnosis and the development of effective treatments. As measurable indicators of how our bodies or organs are functioning, biomarkers can help detect the presence or progress of disease, and identify patients who may benefit from particular therapies. Traditional biomarkers include C-reactive protein (or CRP), which is used in clinics worldwide as a measure of inflammation in the blood, and can help identify people with diseases like rheumatoid arthritis. Similarly, measuring the level of albumin proteins in urine allows doctors to monitor the progression of chronic kidney disease.

Biomarker tests that measure proteins such as CRP and albumin are quick, inexpensive, accessible and minimally-invasive, using small samples of blood or urine. However, such fluid-based biomarkers are not yet widely-available for detecting or monitoring neurodegenerative diseases. EPND is planning to change this, by helping researchers find and access high-quality clinical samples and accompanying data from neurodegenerative disease research studies. This platform will exist as the European node of the AD Workbench of the Alzheimer’s Disease Data Initiative (ADDI), a US-based medical research organisation committed to increasing interoperability of data platforms and accelerating dementia research globally.

“With the potential to make data accessible from more than 120,000 research participants, in partnership with over 60 European cohorts, EPND will provide vital information to scientists, researchers and clinicians.”

Niranjan Bose

“Alzheimer’s and Parkinson’s cost millions of lives and will create an estimated economic burden in Europe of EUR 267 billion by 2030. EPND will answer this massive challenge... bringing together European teams, samples and data.”

Pieter Jelle Visser

What is EPND and what do you hope to accomplish?

EPND is the European Platform for Neurodegenerative Diseases, a 5-year project that receives funding from the European Commission and European pharmaceutical industry (via EFPIA, the European Federation of Pharmaceutical Industries and Associations), under the auspices of the Innovative Medicines Initiative (IMI) 2 Joint Undertaking. EPND has an initial budget of EUR 19,005,502 and was launched in November 2021.

Our ultimate goal is to establish a data and sample infrastructure that will accelerate the discovery of biomarkers, new diagnostics and treatments for neurodegenerative conditions such as Alzheimer’s and Parkinson’s disease.

Specifically, EPND will integrate existing initiatives and European research programmes to build a scalable, sustainable and collaborative platform for storage and analysis of high-quality collections of clinical samples and accompanying data from neurodegenerative disease research studies. This platform will exist as the European node of the AD Workbench of the Alzheimer’s Disease Data Initiative (ADDI), a US-based medical research organisation committed to increasing interoperability of data platforms and accelerating dementia research globally.

Beyond establishing the EPND platform, we will carry out a range of case studies, performing analyses to discover and validate new biomarkers, and leverage this work to...
help fine-tune the data platform functionality. We will evaluate existing standards for data and sample collection, and develop new standardised protocols for EPND contributors and the wider research community. Thereby, we will create agreed principles to enable access to samples and data, establish fair and transparent governance and processes and achieve self-sustainability after five years.

Together, we believe these activities will help accelerate and simplify innovation in the areas of R&D, regulatory, clinical and healthcare practices, for the benefit of researchers, clinicians and patients worldwide.

Why is this important?

Neurodegenerative diseases such as Alzheimer’s and Parkinson’s disease impact millions of lives and will create an estimated economic burden in Europe of EUR 267 billion per year by 2030. There are currently too few available treatments that can effectively prevent or treat these progressive and disabling conditions, and people are often diagnosed at later stages of disease when they are less likely to benefit from such treatments.

To develop effective diagnostics and treatments for neurodegenerative diseases, we need better biomarkers. Biomarkers can help with the early detection of disease, assessment of treatment efficacy, and stratification of patient cohorts for clinical trials. However, currently-available biomarkers involve expensive procedures, such as PET scans of the brain. While there is substantial research on neurodegenerative diseases within Europe, finding and re-using the samples and data from these projects can be challenging, making it hard to validate novel biomarkers that could be measured using more affordable and accessible tests.

EPND will address this challenge head-on. By establishing a secure platform that enables responsible sharing of high-quality clinical samples and data, EPND will empower researchers to develop and validate new biomarkers for neurodegenerative diseases, supporting the development of diagnostics and therapeutics.

"The EPND platform will move us towards a new era of comprehensive data discovery, harmonisation, storage and analysis, by virtue of a core workbench concept that builds upon national and international data infrastructures.”

Anthony Brookes

Who will be able to access and use EPND and what will you do to protect personal data and medical information?

Data and sample providers, researchers from industry and academia, and funders of neurodegenerative research will be able to request access to EPND. We will ensure that contributors and users of data and samples operate responsibly, securely and ethically, protecting the fundamental rights of research participants in full compliance with the EU GDPR.

We will guarantee that subject confidentiality is protected, ensure that resources are used in a manner consistent with informed consent, so as to respect each individual’s choice to share – or not share – their clinical data and samples, which will be appropriately de-identified. There will be a strict access policy for data hosted within or findable and requestable via the EPND platform, with robust data safeguards and a Data and Sample Access Committee for ethical governance of data use and sharing.

Who are the partners in EPND?

Collaboration is at the heart of EPND. EPND brings together a consortium of 29 expert partners from public and private organisations: from European research infrastructures for biobanking and data, to academic institutions, pharmaceutical companies and patient associations – including Alzheimer Europe. EPND is led by two academic partners, Maastricht University and University of Leicester, two EFPIA partners, Gates Ventures and UCB Biopharma.

We are also working in partnership with over 60 European research cohorts, from many different countries across the EU. Through this partnership, EPND will provide appropriately controlled access to high-quality samples and data from more than 120,000 individuals with neurodegenerative disorders, and over 45,000 controls, with new individuals expected to be added annually.

Building on these collaborations and partnerships, EPND will deliver on the promise of big data to rapidly generate new knowledge and share emerging insights – helping to improve the lives of people with neurodegenerative diseases.

"Disjointed and uneven access to samples and data presents a huge challenge for academia and industry. EPND will bring together the neurodegenerative disease community ... developing a Europe-wide platform with global reach through the partnership with ADDI.”

Phil Scordis

Acknowledgement

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Alzheimer Europe has published its Dementia in Europe 2021 Yearbook, examining the subject of dementia inclusive communities and initiatives. This issue was previously examined in the 2015 edition of the Yearbook, at a time when there was less of a policy focus on the subject, particularly at a European and international level.

Since this time, there have been a number of global and European developments which have helped prioritise dementia-inclusive initiatives and communities as a policy issue, with additional resources and materials being developed to support the implementation.

The increased policy focus, resources and funding for dementia-inclusive initiatives and communities has been welcome, encapsulating broad thematic areas including awareness-raising, anti-stigma, inclusive communities and involvement in decision-making.

In early 2021, Alzheimer Europe surveyed its members, asking about the work and activities taking place in their countries, gathering information on the themes and details of the initiatives taking place across Europe. In particular, the survey sought to understand the current policy context of dementia inclusive initiatives across Europe, including crucial elements such as stakeholder involvement, funding, objectives and evaluation.

Furthermore, Alzheimer Europe collated examples of good practice included within the survey responses, seeking to provide useful examples which could potentially be replicated and spread across Europe. The report is divided into the following areas:

- Current policy context of dementia-inclusive communities and initiatives
- Dementia-inclusive communities/initiatives – concepts and models
- Governmental policies – embedding dementia inclusiveness
- Awareness raising campaigns – development and implementation
- Dementia Friends and other training programmes
- Involvement of people with dementia and working groups
- COVID-19
- Good practice examples.

**Report recommendations**

The findings of the report show an extensive amount of work being undertaken across Europe, in line with the policy developments in this area. Whilst it is unsurprising that much of the work around dementia inclusive communities and initiatives continues to be led by our member associations, it is welcome that governments (at different levels) appear to be taking a greater role (whether through funding or participation) in different types of work, including awareness raising or undertaking work to become more dementia inclusive.

However, there remain gaps and a number of areas for improvement, with involvement of people with dementia and their carers remaining highly variable, as well as the monitoring and evaluation of programmes being inconsistent. The Yearbook makes the following recommendations:

- People with dementia and carers should be involved in the development, implementation and monitoring of dementia-inclusive initiatives and communities
- National, regional and local governments should provide sustainable and ongoing funding for projects and initiatives to create dementia-inclusive communities
- National, regional and local governments should utilise the findings from existing work in the development and implementation of their own dementia inclusive-societies and initiatives
- Structured and continuous monitoring and evaluation of dementia-inclusive societies should be undertaken, particularly for cities and municipalities who self-describe as being dementia inclusive etc. using a universal or at least European evaluation framework
- The European Commission should dedicate funding for projects which empower people with dementia and their carers including for dementia-inclusive societies and initiatives.

The Yearbook will be available for download on 22 March 2022, via: [https://www.alzheimer-europe.org/resources/publications](https://www.alzheimer-europe.org/resources/publications)
Sex, gender and sexuality in the context of dementia: new report by Alzheimer Europe’s ethics working group

Alzheimer Europe has published a new report on sex, gender, and sexuality, exploring these issues in the context of dementia and how these may impact on the lives of people with dementia.

In 2021, Alzheimer Europe’s ethics working group explored the topic of sex, gender and sexuality in the context of dementia. The group was composed of experts in the fields of dementia, gender studies, ageing, ethics, psychology, service provision and the training of healthcare professionals. There were members of the group with and without dementia, and with different gender identities and sexual orientations.

The aim of this work was to promote the right of every person with dementia, irrespective of their sex, gender identity and sexual orientation, to be treated with respect and to have access to timely diagnosis, treatment and good quality care and support. This work was part of Alzheimer Europe’s ongoing ethical reflection on issues which impact on the lives and wellbeing of people with dementia, in terms of what is ethical (i.e. right or wrong, morally defensible or not, fair or unfair etc.) and how we ought to live with and treat one another.

The report has three key sections which explore the experience of seeking and obtaining a diagnosis, people with dementia living out their gender and sexual identities and accessing and using professional services, support and care.

Sex, gender and sexuality are closely interrelated and cannot be neatly separated into distinct categories but the working group carefully teases them apart for the purpose of reflection and to challenge moral judgements based on ageist or disablist assumptions (about what is appropriate for older people and people with cognitive difficulties). The report highlights how heteronormative assumptions negatively impact on the lives and wellbeing of so many people with dementia. These are taken-for-granted assumptions about heterosexuality, which rest on biased, narrow-minded and discriminatory beliefs and attitudes towards LGBT* people and on the belief that heterosexuality is the default, preferred or normal mode of sexual orientation.

The report highlights and explores the different experiences, as well as common issues, that cut across one or more gender or sexual identities (e.g. male, female, intersex, bi-gender, gender fluid, trans, non-binary, straight, lesbian, bisexual or gay). It also considers how other factors, such as ethnicity, disability, levels of literacy and education, religiosity and spirituality, as well as socio-economic status, affect the experience of men and women of different gender/sexual identities.

It is important to look at structural discrimination against women throughout their life course but also at the specific experiences and challenges encountered by LGBT* people with dementia and their carers/supporters. People with dementia have complex, intersecting identities and may experience different types and levels of discrimination. We emphasise the need to challenge the tendency to attribute blame for failings in dementia care to low-paid, predominantly female care workers, and to advocate on behalf of predominantly female, unpaid carers regarding issues such as loss of income and pension entitlements, as well as practical and emotional support. Drawing on the concept of microaggression, we demonstrate how subtle discriminatory treatment and hostile attitudes and behaviour towards certain groups in society, based on their sex, gender or sexual orientation, as well as violence per se, unfortunately persist and need to be challenged.

We hope that the report and recommendations will raise awareness about some of the invisible, marginalised and ignored groups of people who have dementia and their carers or supporters. We also hope that this report will contribute towards giving them a voice and that unequal and discriminatory power structures and societal inequalities will be taken on board by policy makers, researchers, current and future health and social care professionals and members of the public.

Members of the expert working group:


The Ethics Report is available to download at: https://www.alzheimer-europe.org/reports-publication/sex-gender-and-sexuality-context-dementia-discussion-paper
Alzheimer Europe hosts Alzheimer’s Association Academy sessions on dementia-inclusive communities and on gender, sex and sexuality in dementia

On 19 October and 16 November 2021, Alzheimer Europe held two online sessions of its popular Alzheimer’s Association Academy series. These two sessions explored themes around dementia-inclusive communities, resources and centres, and gender, sex and sexuality in dementia, respectively.

Alzheimer Europe’s Alzheimer’s Association Academy sessions have been running since December 2015, bringing together the member associations of Alzheimer Europe, members of the European Working Group of People with Dementia (EWGPWD), and experts on dementia from diverse institutions across Europe and beyond. Since the start of the COVID pandemic, these sessions have been held online.

Dementia-inclusive communities, resources and centres

The Academy session on 19 October was focused on European dementia-inclusive communities, and included speakers from the World Health Organisation (WHO), World Dementia Council (WDC) and from European Alzheimer’s associations. The meeting was chaired by Owen Miller, Policy Officer, Alzheimer Europe.

Towards a dementia inclusive society: A WHO toolkit for dementia-friendly initiatives

The first speaker was Katrin Seeher, Department of Mental Health and Substance Abuse, WHO. She spoke about the new WHO toolkit for dementia-friendly initiatives (DFIs), how it was developed and the ways in which it could be implemented. She explained the importance of supportive environments such as DFIs in reducing ageism, stigma and discrimination.

The WHO toolkit was developed in collaboration and consultation with many organisations, individuals and experts by experience, including Alzheimer Europe. It consists of two parts, the first of which sets the scene and provides background information, and the second of which covers implementation, monitoring and evaluation, accompanied by facilitation tools for partners. The next four presentations were aimed at providing examples and learnings about dementia-inclusive activities, initiatives and communities, from organisations based in different countries in Europe.

“T’Monument” – a dementia-inclusive initiative in Mechelen

Kamala Leemans, a local Project Coordinator in the Municipality of Mechelen gave a presentation which focused on the “T’Monument” dementia-inclusive initiative based in Mechelen. T’Monument is a meeting place for people with dementia and their carers, where they can obtain information and peer support, and participate in activities. She emphasised the value of enabling participation and creating judgement-free, community-based spaces for people with dementia and their carers.

Dementia-inclusive initiatives in Italy

Mario Possenti of Federazione Alzheimer Italia focused on describing some of FAI’s work on DFIs and awareness-raising in different communities.

He provided some specific examples of community work on DFIs such as a supermarket chain that has organised dementia-friendly shopping sessions, a cognitive stimulation path created in a public park, and a new network of pharmacies, called “Farmacia, amica della demenza”. Through this initiative, over 19,000 pharmacists took part in training courses and learned useful tips on how to make their premises more inclusive.

Finishing his talk, Mario Possenti presented a recent awareness campaign that was launched for World Alzheimer’s Month, called...
“don’t forget to love me”. This is the title of a song by singer Paolo Ruffini in collaboration with Lorenzo Baglioni. The campaign called for people to sign up to become “dementia friends” and was widely covered in national news media, attracting over 300,000 views and 900,000 interactions, with dissemination via RAI TV, public radio, and major newspapers.

**Dementia Friendly Spots in Slovenia**

Štefanija Zlobec, president of Spominčica – Alzheimer Slovenija (Spominčica means the forget-me-not flower, a symbol that is often associated with dementia) focused on the national Spominčica campaign to create dementia-friendly spots (DFS). The campaign started in 2016 with the establishment of the first DFS at the Slovenian Office of the Ombudsman of Human Rights. Currently, there are 265 DFS in many different places throughout Slovenia: nursing homes, pharmacies, police stations, fire stations, shops, doctors’ offices and schools. Ms Zlobec explained that the goals of DFS are to raise awareness of dementia, to provide services and directions, and to share knowledge – thereby reducing stigma in local communities.

She also described how DFS and Spominčica activities were maintained during the COVID-19 pandemic, keeping telephone lines open and staffed with specialists, providing online activities and support.

**Dementia Friendly Communities in Scotland**

Arlene Crockett, Director of Evidence and Influencing (Dementia), at Life Changes Trust (LCT) explained that since 2015, thanks to an endowment from the UK National Lottery communities fund, LCT has funded 295 organisations across Scotland, benefitting over 20,000 people with dementia and over 10,000 carers. This included funding for over 40 dementia-friendly communities (DFCs) which used the funding to develop resources and initiatives benefiting people with dementia and their carers.

She emphasised that community-based support and top-down, policy-led approaches can work together in complementary partnership. However, the impact of COVID-19 has shown that even more change is needed.

Following this presentation, Helen Rochford-Brennan, member of the EWGPWD, made an intervention in which she called for countries and societies to be held accountable for upholding the rights of people with dementia as laid out in the United Nations Convention on the Rights of People with Disabilities (UNCRPD).

**Evaluating the impact of Dementia Friendly Initiatives**

The final speaker at the Academy meeting was Lenny Shallcross, Executive Director of the World Dementia Council (WDC). He spoke about the findings of the WDC in their evaluation of the impact of DFIs. This work spanned two years between 2018 and 2020, culminating in the publication of a report that outlined their findings.

The report identified three types of DFIs: focused on awareness-raising, enabling participation, or providing support. DFIs in these categories were generally diverse and targeted at different audiences (general public, people with dementia and carers). Mr Shallcross also reflected on the current debate around terminology; dementia-friendly vs dementia-inclusive, and rights-based inclusion.

In closing, he stated that we need to collect better data on the lived experiences of dementia so we can really evaluate the impact of DFCs and DFIs.

**Gender, sex and sexuality in dementia**

The Academy session on 16 November, which was chaired by Dianne Gove, Director for Projects, Alzheimer Europe, was on gender, sex and sexuality in dementia. Representatives of member associations, members of the EWGPWD, representatives from pharmaceutical companies, and Alzheimer Europe staff participated in the session.

**Gendered risk factors for dementia**

The first speaker was Annemarie Schumacher Dimech from the Women’s Brain Project (Switzerland) who provided an overview of gendered risk factors for dementia. She explained the importance of taking into consideration the gender differences in brain and mental health.

She provided some specific examples, which were published in the 2020 report of the Lancet Commission by Livingstone et al. The paper reports 12 modifiable risk factors that account for around 40% of worldwide dementias, which consequently could theoretically be prevented or delayed, including education, obesity, depression and lack of physical activity.
Ms Schumacher Dimech underlined that persistent gender-based inequalities place women at a disadvantage for many modifiable risk factors contributing to dementia.

Quality of life and access to care for LGBTQ+ people with dementia

Linn Sandberg, Associate Professor of Gender Studies, Södertörn University, Sweden discussed “Quality of life and access to care for LGBTQ+ people with dementia”. She explained what research tells us more generally about older LGBTQ+ people and their specific care needs.

In her talk, she emphasised that LGBTQ+ people have a higher risk of cognitive impairment among sexual minority older adults. Risk factors include depression, loneliness and isolation, obesity, poor cardiovascular health and smoking.

People from the LGBTQ+ community who are living with dementia are more likely to reside in care homes, which she said can be linked to the fact that fewer of them have children and that their informal care networks consist of “families of choice” rather than families of origin.

She also presented key published findings on how gay and lesbian people experience dementia and on the understanding of experiences and needs of LGBTQ+ people. Finishing her talk, Linn Sandberg stressed the need for more awareness and training of dementia care staff and highlighted that dementia should not be a barrier to expressing one’s sexual or gender identity.

Relationships and sexuality in care homes

The final presentation was delivered by Aileen Beatty from Akaricare (UK) who spoke about relationships and sexuality in care homes. She first gave a regulatory context on relationships and sexuality in adult social care services from the Care Quality Commission (CQC) – the independent regulator of health and social care in England. The guide, published in 2019, is aimed at CQC staff.

Ms Beatty added that the definition of sexuality is deliberately broad and gave some reactions to this guidance. She described some findings from the 2020 CQC sexual safety report, which highlighted devastating cases of sexual abuse in social care. She also provided some specific examples of experiences of care and the factors which influence the response of staff.

In closing, she gave some recommendations, including focusing on meeting people’s needs in a safe way, while protecting others in care; ensuring that services have sufficient resources to support people to stay safe in the least restrictive way; and the avoidance of language such as abuser / perpetrator in relation to people living with dementia.

Both Academy sessions ended, as always, with a Q&A session, giving delegates the opportunity to question the panel and to discuss the topics in further depth. The next Alzheimer’s Association Academy session is due to take place during February 2022.

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European Alzheimer’s Alliance members set out their views on the year ahead for dementia policy at an EU level

Alzheimer Europe asked members of the European Alzheimer’s Alliance (EAA) for their opinion on which EU policy areas will have the greatest relevance for dementia in the year ahead, and how they intend to help prioritise dementia in their work as MEPs.

Moving into 2022, the legislative and policy agenda of the European Union is well underway, with multiple strands of work that will be relevant for people with dementia, across the areas of health, research and social affairs.

The role of the European Parliament is crucial in helping to keep dementia a priority issue within the policies of the EU. Alzheimer Europe therefore invited members of the European Alzheimer’s Alliance (EAA) to share their views on some of the key policy areas in the year ahead, as well as their own commitment as to how they would help keep dementia as a policy priority.

Sirpa Pietikäinen MEP (Finland), Chair of the EAA

The key EU policy area that will have the greatest impact on people with memory disabling diseases, their families and carers in the year ahead will be the European Health Union. This will allow for more resources, better treatment, improved care and will establish the common European Health Data Space, which will promote better exchange and access to different types of health data to improve diagnostic and preventative aspect.

Accessible environments and accessible living with the help of digitisation, as well as accessible digitisation should be taken into consideration more. The core principles of the New European Bauhaus support this: accessibility, participatory process, people-centred planning, co-creation, bottom-up-approach and sustainability.

I am working for the recognition of dementia as a disability, as it is a condition that causes a cognitive disability and overall has more qualities of a disability than a disease. This is one of the reasons why I personally prefer to use the term memory-disabling disease instead of dementia. However, we need to be mindful of ensuring the rights of patients when their conditions are categorised as disabilities. It cannot serve as a reason to limit patients’ rights or their activity in our societies and we must remember our commitment to the UN Convention on the Rights of Persons with Disabilities (UNCRPD). We need to be mindful of ensuring the rights of patients when their conditions are categorised as disabilities. It cannot serve as a reason to limit patients’ rights or their activity in our societies and we must remember our commitment to the UN Convention on the Rights of Persons with Disabilities (UNCRPD).in our societies and we must remember our commitment to the UN Convention on the Rights of Persons with Disabilities (UNCRPD)."

The basis of all action should be respect and meeting patients from eye to eye. We still have a lot of stigma related to memory-disabling diseases and at some point, we should return to creating a European memory programme. I am glad to lead the Parliament’s Informal Carers’ Group and ensure that memory-disabling diseases are not forgotten there.
Hilde Vautmans MEP (Belgium), Vice Chair of the EAA

The most important instrument this year will be the European Commission’s EUR 5.3 billion EU4Health Programme for 2021–2027 as part of the Next Generation EU Recovery Plan. We have to build a real European Health Union that addresses all needs, including those of people with dementia.

Many programmes funded by the EU tackle several challenges in the fight against dementia. However, several areas are not fully addressed, for example, legal capacity and the rights of persons with dementia.

Therefore, I am convinced we need a comprehensive and coordinated EU Action Plan on dementia 2021–2027 that includes clear indicators, responsibilities and a timeline. This Plan should follow the line of the World Health Organization’s (WHO) global action plan on dementia, focusing on the seven domains and be the main driver for improvements across dementia policy, practice and research.

First, it should officially recognise dementia as a public health priority. Second, it must focus on dementia awareness and friendliness, and reducing the risk of dementia. Moreover, it should enhance dementia diagnosis, treatment, care and support and support dementia carers. Finally, it goes without saying, we must improve information systems for dementia, as well as enhancing research and innovation, specifically in relation to risk factors and the effectiveness of new treatments.

I think this plan should improve living spaces and neighbourhoods ensuring that they are safe, convenient and accessible and that facilitate participation, mobility and autonomy. In the end, the goal should be to improve the quality of life of people living with or affected by dementia.

Finally, it is essential that we implement health in all policies and adequately fund our healthcare systems. We also need well-being indicators and targets within the country-specific recommendations under the European Semester.

We all know that lack of awareness and knowledge about dementia is persistent in many countries. This results in stigmatisation and challenges in early diagnosis and treatment. To address this, I see it as my personal duty to raise awareness online, in the European Parliament and in my city of Sint-Truiden. My father was diagnosed with Alzheimer on his 64th birthday, after which we took care of him at home for ten years until he died. Due to that personal experience, I realise how important it is to increase our awareness and knowledge.

Communities, cities and countries must recognise dementia as a public health priority and improve the care of people with dementia through early diagnosis, comprehensive treatment and support for caregivers. Additionally, we have to scale up public awareness about the condition and educate health and social care professionals. As a member of the European Parliament and as an alderwoman of Sint-Truiden, I will oversee this actually happens, push for a comprehensive Action Plan on dementia and unlock change.

Sara Cerdas MEP (Portugal), member of the EAA

Over the last few decades, the general increase in average life expectancy has brought new challenges to healthcare, which we have been trying to respond to with effective policy measures. Longevity represents one of our biggest challenges today as individuals, considering our higher vulnerability to pathologies such as dementia; as families, which are smaller than in the past, resulting in a lack of an extensive support network and constituting a limiting factor in our response capacity; and as societies, with the progressive ageing of the population, aggravated by the lower birth rate, with greater needs and bigger economic impacts, as a result of the level of health care and social responses required at the later stages of life.

Given all this, it is essential to find solutions at all these levels that respond to the challenges of dementia: new preventative behaviours; therapies that treat these diseases; new responses and support to the growing number of informal caregivers; greater investment in continuous and integrated care networks, which guarantee access to the necessary health and social care and finally, a new model of social
responses that ensure its economic and social sustainability.

Due to the COVID-19 pandemic, the European Union launched its most ambitious health programme ever, EU4Health with EUR 5.3 billion. Among its four main objectives and ten specific objectives, disease prevention and health promotion are prioritised, with international health initiatives and cooperation that allow us to strengthen health systems at across the EU and worldwide, as well as their resilience and resource efficiency, in order to improve accessibility to healthcare.

One of the urgent health priorities that helps pave the way to a true European Health Union was the Pharmaceutical Strategy for Europe, that we hope will make a difference in the medicines available to prevent and treat people living with diseases such as dementia. In 2022, the European Commission will also propose a new framework for the EU pharmaceutical sector, to ensure access to affordable high-quality and innovative medicines for all EU citizens.

"It is essential to find solutions at all these levels that respond to the challenges of dementia: new preventative behaviours; therapies that treat these diseases; new responses and support to the growing number of informal caregivers; greater investment in continuous and integrated care networks."

In the Work Plan for 2022, the European Commission sets out its intention to present a new European Care Strategy to address both carers and care receivers, from childcare to long-term care, that we fully support. This strategy will set a framework for policy reforms to guide the development of sustainable long-term care that ensures better and more affordable access to quality services for all.

Finally, we will discuss the proposal to create a European Health Data Space, that for example will improve research. We will also support the call for the European Commission’s Green Paper on Ageing.

Those are some of the examples that I believe will have a significant impact on people living with dementia, their families and carers. My commitment is to keep pushing forward to make health a top policy priority in Europe, because as COVID-19 showed us, health is a common challenge that we must face together.

Seán Kelly MEP (Ireland), member of the EAA

Dementia is an enormous, long-term medical challenge. There is currently no cure and no disease-modifying treatment. It affects almost 8 million people in the EU and researchers suggest that the numbers of people living with dementia is set to double by 2050. We need to see concerted action to avoid this number tripling.

In addition to the heartbreaking personal impacts of dementia, the economic and societal impacts of the condition are extensive, further strengthening the call for policy makers to work to protect lives now and in the future.

The COVID-19 pandemic has shown us how the right investment and leadership can enable innovative approaches to fast-track life-saving treatments and care. It is time for the same coordinated and ambitious action to make the EU a world-leader in overcoming dementia.

Substantial progress has certainly been made in this area in recent years, but dementia still is not afforded the priority it deserves, considering the number of people affected, the impact it has on those who live with it and their families, and the financial cost to healthcare systems.

"Substantial progress has certainly been made in this area in recent years, but dementia still is not afforded the priority it deserves, considering the number of people affected, the impact it has on those who live with it and their families, and the financial cost to healthcare systems."

I strongly believe that there should be better recognition for informal carers and the impact that dementia has on them. We must ensure that adequate supports and services in place to ensure their health and well-being.

I was delighted to have nominated Family Carers Ireland, the incredibly deserving, non-profit organisation which won the European Citizen’s Prize 2020. Carers play a vital role in society and, even more than most people, have endured great hardships during the COVID-19 restrictions and necessary quarantining, given the health risks posed to those they care for.

Fortunately, since the launch of the Paris and Glasgow Declarations, there has been a considerable increase in the number of countries with dedicated strategies on dementia, including my own, Ireland.

Support for Member States to work towards the implementation of the World Health...
Organization’s global action plan on dementia 2017–2025 must be scaled up, in order to help prevent dementia, and to ensure that those with dementia, and their carers, receive the care and support they need.

Dementia research must be prioritised in EU research programmes and coordination between programmes reinforced. Currently, supported efforts in the area of dementia include the Joint Programme on Neurodegenerative Diseases Research and the European Brain Research Area. The EU has also established the Innovative Medicines Initiative to facilitate collaboration between industry and academia, which includes dementia research.

Europe must adequately prepare for the increasing numbers of people who are likely to develop dementia in the future. Those living with dementia should be able to fulfil their potential with dignity, respect, autonomy and equality, and my colleagues and I in the European Parliament will continue to advocate for dementia as a top health priority at a European level.

Irena Joveva MEP (Slovenia), member of the EAA

The population is getting older and forecasts for the future are worrying, as the number of people with dementia is expected to increase to 13.4 million by 2030. Society still has low education on dementia and low recognition of the importance of early diagnosis. In most cases, people with dementia depend on family members and friends who provide care, yet are not paid for it.

During the pandemic, carers did some of the most demanding jobs without adequate support. There is an urgent need to strengthen support for the people who provide that care, in both formal and informal settings. We need more care, especially since we live in ageing society, however, adequate financing is the thing missing. Sufficient, stable and sustainable financing is important for the long-term sector to be able to provide its services. That is why Commission has stated that EU Care Strategy will be presented at the end of 2022 and will focus on long term and also child care.

Also, an important focus should be on research. In particular, future research should include people with dementia and their careers and families, as research nowadays rarely or does not at all, involve people with dementia.

Although countries have made good progress in implementing public awareness campaigns to improve public understanding of dementia, there is still room for improvement. Awareness campaigns are key to keep dementia as policy priority.

“I need more care, especially since we live in ageing society, however, adequate financing is the thing missing. Sufficient, stable and sustainable financing is important for the long-term sector to be able to provide its services.”

Ivan Štefanec MEP (Slovakia), member of the EAA

Almost 8 million people live with some form of dementia within the European Union, and if we stay passive, this number will almost double by the year 2030. According to experts, the reason for such a high number of patients is not due to the lack of medications under development, but instead the insufficient medical infrastructure, which is not able to detect, treat and care for people in relation to the development of the disease.

In the context of the COVID-19 pandemic, preparation for the creation of a European Health Union have accelerated, which not only means the joint purchase of medications and medical supplies, but also better interconnection of existing health systems and the exchange of information.

I am ready to support any good proposal in this area and to advocate that cooperation should also cover chronic diseases such as
Alzheimer’s disease. However, healthcare itself, under the European law, is in the responsibility of individual nation states. Therefore, any Member of the European Parliament, who has this issue at heart, should follow developments in his or her home country and be in close contact with national institutions and experts. If necessary, they should also put them in touch with workplaces within the European Union that can pass on valuable experience and information.

I myself have a sad experience of the disease in my family, therefore I know, what patients and their loved ones experience during the progression of the disease. There are a number of specialised centres and associations within Slovakia dedicated to patients and their families, providing them with information and lectures on how to make life as easy as possible for the affected person. It is always the case, that the patient, unless they are in an acute condition, always copes better with his diagnosis and accepts treatment better at home than within a foreign environment. That is why I support the work of mobile teams regularly visiting patients in their homes, checking on their condition and carrying out special medical procedures.

The subject of Alzheimer’s disease is interrelated to that of older people, in which I am also intensively involved. Experts agree that the onset of Alzheimer’s disease can be significantly delayed or even completely prevented by an active lifestyle and building social contacts even in older age. It is not just about physical activity though, but also about maintaining a fresh and efficient mind. Lifelong learning, well established within the European Union in the context of the third age universities, is also contributing. I am very pleased that as a part of the increase in funding for the Erasmus + programme, it has been possible to extend it to senior students.

**Any Member of the European Parliament, who has this issue at heart, should follow developments in his or her home country and be in close contact with national institutions and experts.**

**Tomáš Zdechovský MEP (Czech Republic), member of the EAA**

There are many ambitious strategies currently discussed at European level such as the EU Strategy for the Rights of Persons with Disabilities, the European Care Strategy, the Pharmaceutical Strategy for Europe and Horizon Europe. As Alzheimer’s disease (AD) currently does not have effective disease-modifying treatments, the Pharmaceutical strategy could potentially target the innovative approaches, such as the use of psychedelics to treat dementia in the framework of unmet medical needs. There are promising human clinical trials suggesting a possible role of psychedelics in symptomatic treatment of depressed mood and anxiety in early-stage of AD and also potential of psychedelics to reverse brain atrophy, enhance cognitive function, and slow progression of AD.

Regarding the Horizon Europe, of particular relevance for dementia is the health cluster with a budget of around EUR 8 billion which, among other things, aims to protect the health and well-being of citizens of all ages by generating new knowledge and developing innovative solutions. As AD and dementia affect not only individuals with the condition, but their carers and families (who often provide care informally) as well, it is important to speak about their rights because the value of informal care is not, in my opinion, recognised enough. That is why I am glad that the European Commission recently announced the launch of the European Care Strategy.

As AD and dementia affect not only individuals with the condition, but their carers and families (who often provide care informally) as well, it is important to speak about their rights because the value of informal care is not, in my opinion, recognised enough.

In the European Parliament, I am member of various inter-parliamentary groups, for example the MEP Alliance for Mental Health and the Informal Carers Interest Group. We regularly organise events or roundtables to discuss policy priorities and to hear different opinions of stakeholders. Recently, the MEP Alliance for Mental Health organised hybrid event on Innovative Approaches in Mental Health where leading scientists pointed out that traditional treatments no longer provide sufficient help and that public authorities should support innovative approaches.

The MEP Alliance for Mental Health also currently advocates for the 2023 to be the European Year of Mental Health, which should serve as EU-wide awareness campaign to inform and educate European citizens and focus the attention of the governments of Member States and policy makers, in order to change attitudes, behaviours, policy and practice, both at EU as well as at national level.

In addition, there will be a Czech Presidency of the Council of the EU starting in the middle of 2022 and I have been trying to pursue the issue of mental health, innovative treatments and carers rights as one of the policy priorities for the Czech presidency.
European Group of Governmental Experts on Dementia meets online to share dementia policy knowledge and developments

In its final meeting of 2021, the group met online to discuss national policy developments in relation to dementia, as well as presentations from the Global Coalition on Aging and the World Health Organization (WHO).

On 7 December, the European Group of Governmental Experts on Dementia held its final meeting of 2021, exchanging information and knowledge on the latest developments on dementia policy and practice. The meeting was attended by representatives of 19 countries: Austria, Bulgaria, Czech Republic, Finland, France, Germany, Greece, Iceland, Israel, Latvia, Malta, Netherlands, Norway, Portugal, Slovenia, Sweden, Switzerland, Turkey and United Kingdom (England). In addition, representatives from the European Commission (DG SANTÉ and DG RTD), the World Health Organization (WHO) and WHO Europe were also in attendance.

A guest lecture was given by the Global Coalition on Aging (GCOA), sharing details on their work on the Alzheimer’s Innovation Readiness Index, a recent publication which scored countries on their progress in relation to dementia policy across different domains (care and support, research etc.). The presentation focused on the need for governments to ensure funding for the implementation of national strategies, as well as the need for greater investment for early diagnosis and detection programmes, awareness raising campaigns and training programmes for both formal and informal caregivers.

The report is available at: https://globalcoalitiononaging.com/initiatives/#initiative-2237

The group also heard from the WHO on the Global Status Report on Dementia, which takes stock of actions driven by Member States, the WHO and civil society in the implementation of the Global Action Plan on Dementia 2017–2025. It was noted that some progress has been made towards the objectives, particularly in relation to dementia-inclusive societies and awareness raising campaigns. However, many barriers have impeded the implementation of measures (such as the COVID-19 pandemic) and the majority of action areas require significant and urgent action by governments if the targets set out in the plan are to be met by 2025.

The status report is available at: https://www.who.int/publications/i/item/9789240033245

WHO Europe provided an update on its work on the establishment of a European Mental Health Coalition (MHC) which will deliver its programme of work related to the European Framework for Mental Health. Whilst not focused on dementia specifically, it will be included within the workstreams, as the MHC seeks to encourage Member States to prioritise mental health as a public health matter over the next five years. This will include:

- Transforming attitudes about mental health
- Expediting mental health service reforms
- Accelerating progress towards universal health coverage for people with mental health conditions.

An article with additional details on WHO Europe’s can be found on page in the following article.

During the meeting, national experts also presented on policy developments in their counties across a range of issues including the implementation of national dementia strategies, development of resource websites to support people to access services and supports, the development of new models of care and support, as well as guidance on oral health for people with dementia.

The next meeting of the group is expected to take place on 14–15 June 2022 in Brussels (Belgium).
WHO Europe launches Pan-European Mental Health Coalition

The World Health Organization (WHO) Regional Office for Europe has launched one of its flagship initiatives, the Pan-European Mental Health Coalition (MHC), seeking to bring together stakeholders, in an effort to raise prioritise the issue among Member States.

On 30 September, the World Health Organization (WHO) Europe launched a new Pan-European Mental Health Coalition (MHC), dedicated to improving mental health across the WHO European Region. The initiative follows the priorities established by the European Programme of Work 2020–2025 and will have direct relevance for dementia policy, as dementia sits within the framework of Mental Health within the WHO.

The MHC is a partnership dedicated to improving mental health across the WHO European Region. It will target gaps in mental health services by gathering national leaders, professionals, members of civil society, representatives of international organisations and experts to raise the profiles of mental health and encourage Member States to prioritise it as a policy issue within their countries.

The launch event was attended by Queen Mathilde of Belgium, WHO Europe Regional Director Hans Kluge and European Commissioner for Health and Food Safety, Stella Kyriakides. Alzheimer Europe, which had been invited to become a part of the Coalition, was represented at the event by Executive Director Jean Georges.

Key priorities for the Coalition include transforming mental health services, as well as promoting mental health and preventing mental ill-health across the life course. As part of this, there will be a focus on shifting mental health care away from psychiatric institutions to community-based care; scaling up the mental health workforce; protecting and preserving the mental health of children, adolescents and young people; and strengthening initiatives to promote healthy ageing among older adults.

In addition, the MHC will:

- Provide an overarching structure for exchanging experience and mobilising national champions, advocates and service innovators
- Act as the umbrella for a multi-agency, region-wide review of lessons learnt and future perspectives for mental health policy formation and implementation
- Stimulate fundamental and applied research on mental health, with particular attention to the interface between health, social and community care and the role of primary care; the intersection between mental health and gender and the role of temporary or chronic financial insecurity
- Facilitate national policy dialogues on mental health and psychosocial support to incorporate key mental health priorities in national policies and plans (such as cross-sector prevention; digitalisation of mental health services; de-institutionalisation of psychiatric care and investment in commensurate community structures; collaboration between health and social care networks and forensic mental health).

These priorities will be supported by leadership-building and advocacy initiatives, mental health literacy programmes, and a mental health data lab that will amass data on key indicators of population mental health to better serve all European countries in providing timely, affordable access to health care.

More information on the Pan-European MHC can be found at: https://www.euro.who.int/en/health-topics/health-policy/european-programme-of-work/flagship-initiatives/the-pan-european-mental-health-coalition
Regional technical consultation

On 15 and 16 February 2022, an online regional technical consultation on the implementation of the European Framework for Action on Mental Health 2021-2025 was held, with attendees from national governments, WHO offices across Europe and civil society participating. During the event, presentations were delivered by different stakeholders, highlighting the scale of the challenge presented by mental health, with the WHO leadership noting that even pre-pandemic, mental health services had historically been more poorly funded compared to other areas of healthcare systems. Across the two days, WHO Europe outlined the rationale and approach of their work around mental health. Furthermore, stakeholders from across Europe, including government officials and civil society organisations, provided examples of programmes and policies which have reformed mental health systems and have provided improved outcomes for patients.

On the second day, Alzheimer Europe Executive Director, Jean Georges, spoke during the session entitled “Healthy lives and wellbeing at all ages: Promotion and protection of Mental health over the life-course”. Addressing attendees, he highlighted the disproportionate effect that the COVID-19 pandemic has had on people living with dementia, both in relation to mortality rates, but also on the mental health of those living with the condition, as a result of measures such as lockdown and isolation. In addition, he noted the potential benefits of a greater focus on prevention throughout the life course, citing the Lancet Commission on Dementia 2020, which estimated that as many as 40% of dementia were linked to modifiable risk factors.
World Dementia Council report measures progress against international commitments

Throughout 2013, the World Dementia Council (WDC) held global dialogues to establish how much progress had been made against the G8 Communiqué in 2013. In this article, WDC Executive Director, Lenny Shallcross, outlines the background to the work and why there is cause for optimism.

COVID-19 has been the health crisis that has dominated the attention of governments and health systems around the world for the last two years. It has dominated the lives of all of us, to such an extent that our lives pre-COVID feel like a faraway land.

Some health crises, like COVID-19 or HIV, burst out of nowhere. Others slowly, progressively, relentlessly, build. When Alois Alzheimer’s first described the disease more than a century ago, the average life expectancy in Europe was around 50. Today it is over 80!

Year-by-year, as more of us thankfully live into old age, the number of people living with dementia has increased and will continue to increase. Alzheimer Europe estimates that the number of people living with dementia in the European Union will increase over the next thirty years from 7.8 million to 14.2 million.

The almost doubling of the number of individuals living with dementia, in just three decades, could be viewed as a cause for despair. Today a physician in Europe is no more able to prescribe a treatment that will slow or stop Alzheimer’s disease (AD) than at the beginning of the twentieth century. A period of time where treatments for other diseases, many cancers for example, have been revolutionised, fundamentally changing patient prognosis.

Research landscape

Despite the fact that today there is no approved disease modifying treatment for AD or other dementias within Europe, I believe there are reasons for optimism. We know more about the science of the disease than ever before. In part, the acceleration in science is happening because of technology and data. Also in part, and this is key, the acceleration is because governments, and particularly the United States government, have increased funding for dementia research over the last decade.

There have been huge advances in the development of blood-based diagnostics that we will soon see being used for the first time in clinical trials and then clinical practice. And probably, a little further down the line, there will be new digital diagnostic techniques as well. While the international dementia community may debate the effectiveness of aducanumab, it is agreed that the progress we have made in understanding the science is going to mean in the decade ahead we will achieve and deliver disease-modifying treatments.

Looking ahead, there are good reasons to be optimistic. Yet while there are grounds to be confident about the direction, the pace of progress is less certain. For all the advances made, progress in developing treatments for AD and other dementias has been too slow.

World Dementia Council

The World Dementia Council was established by the UK government following the G8
London dementia summit hosted by the then UK Prime Minister, David Cameron, in 2018. After the ministerial G8 meeting, governments committed to advance research, improve care, raise awareness and increasing understanding of risk reduction and prevention. The UK government, on behalf of the G8, established the Council to support and challenge the international community to deliver on the commitments made at the London summit.

“In too many countries, in too many communities, dementia remains in the shadows. Understanding and awareness of dementia remain low compared to other diseases.”

The Council has 24 members, international leaders drawn from academia, industry, advocacy, finance and the care sector. There are two Council members who are living with the condition. Alongside them are associate members from a number of governments. The Organisation for Economic Co-operation and Development (OECD) and World Health Organization (WHO) also sit on the Council. The chair is Professor Philip Scheltens, Director of the Alzheimer’s Center at Amsterdam University with Professor Kiyoshi Kurokawa, Chair of the Health and Global Policy Institute in Japan, who is the Vice-Chair.

The Council works through international advocacy, international leadership and building global networks. We report on the progress the international community is making and make recommendations on how that can be accelerated. We bring together the international dementia community, policy makers, government ministers and advocates at summits, such as one in London in 2018 and Tokyo in 2019 and a virtual research summit meeting held at the end of last year.

Dementia Landscape Project

Over the last year the Council has been conducting the Dementia Landscape Project. This project is a global initiative by the Council to review international progress made against the commitments the G8 made in 2013. The project brings together international leaders across the areas of research, care, awareness and risk reduction.

Over the last year, we have held 13 virtual global dialogues. These have been on different themes that were highlighted by the G8 in the ministerial communiqué. These include the development of treatments, global clinical trials, data sharing, prevention, care, technology and others. Along with looking at these themes there have also been dialogues around dementia in low-and-middle income countries and a dialogue for people with lived experiences of the condition.

Over 400 international leaders have participated. Alongside publishing the transcripts of the discussions, we have published collections of essays exploring the different themes. This spring, the Council will publish a report bringing together the discussions and identifying areas where governments, policy makers and the community can accelerate progress. The report will be launched at a summit meeting in London at the end of March.

Societal landscape

The commitments made by the G8 were not just about advancing research, but improving care and raising awareness of dementia. Too many people today receive poor quality care and families do not get the support they need. In too many countries, in too many communities, dementia remains in the shadows. Understanding and awareness of dementia remain low compared to other diseases, as Alzheimer’s Disease International highlighted in a recent report. Challenges remain in advancing the science and developing better diagnostics and treatments. The G8 also committed to making improvements in understanding risk reduction and preventing people developing dementia in the first place. There is now much better evidence about the impact of early and midlife on later life and around the development of dementia in later life.

The Dementia Landscape Project looked at all these areas and heard from different global experts. It is tempting to think that science will “solve” dementia. There will perhaps, in the future, be treatments that stop the development of dementia. But in the immediate years ahead treatments will only slow the development of the disease — although this extra time will bring huge benefits, to individuals and families. Better awareness, better care and better prevention will all be important parts of the policy makers arsenal in defeating dementia.

These challenges sit within, and are key to, the broader challenge confronting policy makers around the world: the ageing society. A lot of the public policy challenges today come down to adapting systems that were set up to look after the health of working age adults. When health and social care systems were set up in most European countries, people did not live long after they stopped working. We have spent the last couple of decades trying to make the health and social care system work for an entirely different society where people live 15 or 20 years after retirement. Treatments that slow the disease will, paradoxically, increase this challenge. And treatments themselves will throw up new challenges that the field has not yet confronted, like access and equity. These are all questions the Council, with collaborators from around the world, will further explore in the year ahead.

More information on the dementia landscape project can be found at: http://www.worlddementiacouncil.org/DLP

“Challenges remain in advancing the science and developing better diagnostics and treatments. The G8 also committed to making improvements in understanding risk reduction and preventing people developing dementia in the first place.”
Muistiliitto publishes research on the social dimension and impact of dementia in Finland

In September 2021, Muistiliitto jointly published a report with Biogen, highlighting the growing number of people with memory disorders and the associated financial costs it will cause to Finnish society. In this article, Muistiliitto CEO, Katarina Suomu, outlines the background to the report and its recommendations for policy-makers.

The social impact of memory disorders

Finland has one of the most rapidly ageing societies. Alzheimer’s disease (AD) and other memory disorders are among our biggest public health challenges. One important mission of Alzheimer Society of Finland (Muistiliitto) is advocacy work – how to have an impact on the society and make it better for people living with memory disorders and their carers. We aim to raise awareness, produce and spread information about memory disorders both on individual and social level.

People in general are today quite well informed about AD and we see and read more and more articles and stories about it in media. At the same time the need for relevant, specific and topical information is constant. The organisation of public healthcare and social welfare will be reformed in Finland. The responsibility for organising these services will be transferred from municipalities (currently around 300) to 22 wellbeing services counties from 2023. The key objective of the reform is to improve the availability and quality of basic public services throughout Finland. The Finnish Alzheimer Society hopes that the reform may create better and more equal services to people with memory disorders and their carers.

Muistiliitto has, from time to time, had some joint projects with Biogen Finland and now it felt natural to combine our expertise to do something to open discussions on this urgent challenge: the growing number of people with memory disorders and the financial costs for society.

We saw there was a demand for a report that would both promote the rights of people with memory disorders and address the decision- and policy-makers. The summary briefly describes the basic facts about the prevalence of the disease, possibilities of prevention and the current and future demand to our service structures.

Together we formed a small working group including representatives from our local members associations. We thought it was important to have practical experience and knowledge from various areas around the country, that we could combine to national level recommendations.

One key element of the report is a description of AD or other memory disease patient’s path in health care and social services. The

Key Point 1: Adequate care helps to control the financial costs of memory disorders

- Finland needs a national description of care and service pathways for people with memory disorders. The pathway has to be followed everywhere and in all the future wellbeing counties.
- Timely provision of rehabilitation and care may put back the need for residential care.
- Carers of people with memory disorders need individual support. Legislation concerning carers support has to be more flexible.
- Forthcoming wellbeing counties (new health and social care providers) must do development work with carers and local associations and must be based on scientific knowledge.
- More education and training is needed for memory clinic staff and different professional roles have to be clarified.

Key Point 2: Early prevention and timely diagnosis prevent financial costs

- Prevention of memory disorders and highlighting the importance of brain health has to be executed across the lifespan.
- We need better awareness of AD and we need to add information on services concerning it, including the services provided by the third sector, e.g. NGOs.
- Investment in early diagnosis is important. Memory disorders must be screened in occupational health services and in clinics for the elderly.
- In basic health care services and occupational health services, professionals need stronger knowledge and competencies about memory disorders.
Alongside designing the patient’s path, some written sources were created, specifically in relation to outlining statistics and former policy actions. The Nordic Healthcare Group was one of the project partners and they interviewed both carers and stakeholders in order to supplement the content of the report. Material of the interviews verified and complemented the patient’s path created by the working group. What usually works well and what doesn’t from the point of view of the patients and carers themselves, is included in the report through quotations (both indirect and direct). Together all the material gave us a brief but comprehensive picture of dementia care on a personal and social level. The actual report was produced by Rud Pedersen Public Affairs.

Policy recommendations at the end of the report are presented under two equally important key points. The first key point is how adequate care is helping to control the financial costs of memory disorders. The second, equally important key point is, how early prevention and timely diagnosis also prevent the financial costs. The report with its policy recommendations was published in an online launch event on 21st September 2021, on a World Alzheimer Day.

Memory barometer

The content of the report fits well with our broader policy work and can be utilised in different occasions and for various target groups, also other than policy- and decision-makers.

Muistilitto published its Memory Barometer 2020 as a continuum to previous barometers and National Memory Plan. Findings of the 2020 barometer are valid and used as a source for writing this report.

According to the latest barometer, in the last five years, the services for people with memory disorders and their carers have developed positively in general. For example, there are more professionals working in the field and their competencies have increased. However, the barometer has also shown that we need to improve the knowledge and competencies related to memory disorders and build on progress already made.

The Memory Barometer reports 16 conclusions in total. They are not formed as recommendations owing to the nature of the barometer. However, the findings are identical, than those of the social impact report. One rather alarming finding is that people with early onset memory disorders don’t get the help and services they need. Their children, sometimes underaged, also do not receive support and their needs may simply be ignored. The position of people with an early onset memory disorder will be an important topic for development work and advocacy in the future. Let’s hope the current big service reform will bring some positive progress to that too!
Changing of the guard: INTERDEM has a new Chairperson in 2022

Myrra Vernooij-Dassen stepped down as Chairperson of the INTERDEM network (Early detection and timely INTERvention in DEMentia) at the end of 2021. She is succeeded by Marjolein de Vugt. We spoke to the outgoing Chairperson about her time in the role and to the Chairperson-elect about her goals and hopes for the future.

Myrra Vernooij-Dassen

You joined INTERDEM in 1999 and became Chairperson in 2009. What did you hope to achieve during your time in the role and did you manage to reach your goals?

My main goal was INTERDEM taking responsibility for the complex field of psychosocial dementia research. Chairing INTERDEM is a team effort carried out with its board. We tried to provide guidance by Manifestos in which we indicated the strengths and weaknesses of psychosocial dementia research and set the research agenda.

A major strength was the state of psychological interventions, but social aspects in the context of dementia were not clearly articulated. Since dementia is a multifactorial syndrome we consider that at least the three health domains formulated by the WHO, physical, mental and social health, should be intensively explored. This requires interdisciplinary collaboration. However, a major weakness in dementia research is working in silos rather than interdisciplinary.

The urgency for interdisciplinary research also arose from my participation in the ongoing debates in the Scientific Advisory Board of the Joint Programme Neurodegenerative Diseases (JPND). This led to another goal: psychosocial research taking its place in dementia research.

Taking responsibility does not only mean providing guidance, but particularly stimulating and facilitating new initiatives from the network. It was a pleasure to work within an atmosphere of ambition and friendship. The INTERDEM network is flourishing and I am very confident that it will continue to do so with Marjolein de Vugt as the new Chair.

What initially sparked your interest in and passion for dementia research?

There was no initial spark; there was fear for dementia. I was trained as a nurse and medical sociologist and wanted to become a researcher when a job was offered to me on dementia research in nursing homes. I hesitated, because dementia was a theme I wanted to avoid. However, I got the job, struggled with my fear and managed to overcome it by curiosity taking over.

Years later, life itself made it impossible to avoid dementia in my own social environment. The value of our work for daily practice was beyond my expectations.

My family benefitted a lot from our gained knowledge. Most important was blaming dementia for changed behaviour and us continuing to keep our mothers included in their favourite role as mothers (in-law) and grandmothers. I did not perceive their years with dementia as lost years, I am grateful for having had this time with our mothers (in law), making it at the very end acceptable to let them go. These experiences made me even more motivated to collaborate with people with dementia.

Can you share some personal highlights from your time as Chairperson and some of the main achievements of INTERDEM so far?

The growth and thriving of INTERDEM is a continuous highlight. It is the world’s largest network on psychosocial interventions with a very high attendance of yearly meetings in which we inspire each other and enjoy being together, even virtually.

Like in the early years there is still a spirit of exchanging new developments and our meetings provide a platform to new initiatives. These include new research proposals and building new structures such as the
INTERDEM Academy for early career researchers and taskforces dedicated to key themes such as technology.

INTERDEM is a prominent supplier of key publications including articles on effectiveness of psychosocial interventions and books describing available INTERDEM interventions.

Our website makes all this accessible to everyone interested in psychosocial interventions worldwide. Last but no least is the pleasure of working within this wonderful network, with close board collaboration and connections with other organisations including Alzheimer Europe and International Psychogeriatric Association (IPA). It was a privilege to be in the position to facilitate and initiate developments.

**As such a passionate psychosocial dementia researcher, do you plan to continue your work in this area and if so, in what capacity?**

I am already an emeritus professor for six years. In the Netherlands we enter the emeritus status with a lecture providing suggestions for future research. I promoted social health in dementia research. This made me move from intervention research to more fundamental research on mechanisms in the relationship between social health, cognition and dementia. I will continue these efforts. My preferred position is being a continuously learning student and researcher. My activities are embedded in my positions as member of the INTERDEM board, the scientific advisory board of JPND, as Chair of IPA’s webinar series, member of several project advisory boards and of research projects. I am curious on what the future will bring.

**Marjolein de Vugt**

**Congratulations on your appointment as the new Chairperson of INTERDEM. Why did you decide to take this position and what are some of your hopes for the future?**

Twenty years ago I was a young PhD student and I got introduced to INTERDEM. An international network laid at my feet, which is not self-evident when you are in your early days of your research career. Since then INTERDEM gave me so much opportunities, for example to contribute to joint papers such as the European consensus paper on psychosocial outcome measures.

It brought me possibilities to join European projects, for example the Actifcare project funded by JPND. And it gave me opportunities to shape the European psychosocial research agenda, for example by contributing to the INTERDEM manifesto.

My experience is illustrative of the power of INTERDEM, to give all opportunities to individual researchers to contribute and to collaborate and together take a strong position in the field of psychosocial research in dementia.

Collaboration is key to address the complex challenges of dementia. INTERDEM has flourished under the leadership of Chair Prof. Dr Myrra Vernooij-Dassen and co-Chair Prof. Dr Esme Moniz-Cook.

I’m very honoured that the board has elected me as the new Chair of INTERDEM and I see it as my mission to maintain the strengths of INTERDEM within a positively stimulating environment for all members.

My hope is that we can bring psychosocial research forward and to give this an even stronger and essential place in research and practice.

You have started in this new role during an ongoing global pandemic and public health crisis. Are these challenging circumstances impacting on the work of INTERDEM and if so, how are you adapting to overcome them?

INTERDEM grows and flourishes not only because of the expertise and enthusiasm of the researchers involved, but also because of the pleasure of working together across borders. Over the years, many friendships have developed within INTERDEM. Meeting each other, working together on projects and discussing highlights and new perspectives in the psychosocial research field has been important for the success of INTERDEM.

The pandemic has challenged our collaboration in research projects and proximity in the collaboration. But I’m proud that in these challenging circumstances we continued our collaboration online in dedicated task force meetings even outside our ongoing projects.

The commitment of our members is also reflected in the attendance of more than one hundred people in our annual online INTERDEM meeting preceding the Alzheimer Europe Conference and the many contributions of our members to the conference.

“Collaboration is key to address the complex challenges of dementia. INTERDEM has flourished under the leadership of Chair Prof. Dr Myrra Vernooij-Dassen and co-Chair Prof. Dr Esme Moniz-Cook.”

Marjolein de Vugt
During your recent address to delegates at the 31st Alzheimer Europe Conference, you spoke about the INTERDEM Academy. Can you tell us more about this project and why you feel it is of key importance?

I’m very proud that we not only have a senior network of research leaders but also a growing network of young researchers in our INTERDEM Academy. These young researchers are our future and INTERDEM feels committed to foster their talent and to support them in their pathway to senior positions in the field for example by organising schools and masterclasses and to grant fellowships.

In the coming years I would like to further strengthen the connection between the senior INTERDEM network and the Junior Academy, for example by involving academy members more closely in the activities of the task forces and the board. I believe this will strengthen our network, give more manpower to our activities and it will support young researchers in their pathway to senior positions in the field.

INTERDEM works closely with Alzheimer Europe and its European Working Group of People with Dementia. How important is this collaboration for the work of INTERDEM?

The partnership agreement that we have with Alzheimer Europe shows our joint commitment to care for people with dementia and their carers.

We are grateful for the way Alzheimer Europe has facilitated INTERDEM in their annual meetings and contributions to the annual conferences. Alzheimer Europe strengthens the voices of people with dementia and their carers to influence practice and policy, but also strengthens their voice in research. INTERDEM has reaped the benefits of this, for example by working closely with the European Working Group of People with Dementia in the INDUCT and DISTINCT consortia on technology and dementia.

Their perspectives and experiences are the driving force in our research and essential to create meaningful changes in perceptions, practice and policy in order to improve the quality of life of people with dementia and their carers. I hope there are many years to come in our continued collaboration.

For more information, visit:

https://interdem.org/
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Sabine Jansen reflects on her time as Executive Director of Deutsche Alzheimer Gesellschaft

Sabine Jansen stepped down as Executive Director of Deutsche Alzheimer Gesellschaft (DAlzG) at the end of 2021. She remains Chairperson of the DAlzG Foundation and a Board member of Alzheimer Europe. In this interview, she discusses her time at DAlzG and shares the achievements she deems most important. She is succeeded in her role by Saskia Weiß.

You joined the Deutsche Alzheimer Gesellschaft in 1997 and became its Executive Director in 2000. What were your reasons for taking this position at DAlzG and why have you decided to step down at this time?

In 2000 the organisation was very small. Only four people were working for it. There was much to do but we also had the great opportunity to shape the organisation. It was much fun to work in all fields of dementia: counselling, public awareness, support volunteer member organisations, advocacy and more. It has never been boring up to today. After more than 24 years working for an organisation I felt that this can be enough. 18 people are working in the office of the national association now. A wonderful team! The number of members has grown from about 35 to now 135 independent regional branches. A good time to step down and keep my life more quiet, but I will stay as Chair of our foundation and do not leave too far.

Can you share some highlights from your time as Executive Director? What do you think has been the biggest achievement of the DAlzG so far?

I have experienced many highlights. Our biggest project in the beginning and up to today is our helpline. Mainly caregivers but also people with dementia, professional and volunteer carers were seeking for help and advice. The helpline will celebrate its 20th anniversary next year and has had far more than 100,000 contacts over the years. It still gets funding by the Ministry of Family Affairs.

On the political stage the biggest success, in my opinion, was the reform of our long term care insurance. When it was set up in 1995 the German Alzheimer Association complained that people with dementia were not adequately seen with their needs. In 2006, the former Health Minister, Ulla Schmidt, established an advisory board to make suggestions to correct this. I was member of this advisory board for many years and very happy that after some small changes in law and some health ministers later in the year 2015, a big reform was decided in the time of Health Minister Hermann Gröhe.

Another success in the year 2019 was the launch of the national dementia strategy after many years of preparation. One of the measures is our dementia friends programme with support from the Ministries of Health and Family Affairs.

What are your hopes for the organisation’s future? Do you have a few words of wisdom for your successor?

If I first look back I can see that we have had a tremendous development in the field of dementia. 25 years ago the knowledge about the disease was much smaller. Nearly no information materials were available. Today we have books, films and awareness campaigns. The picture of dementia has changed. Concepts of good dementia care have been developed. On the other side there is still much to do. Support to all people with dementia and their families should be given as they need it. I see one big challenge to come: My generation (“the baby boomers”) is big. Already nowadays we experience a lack of professional caregivers and this will get even worse in the future. One way can be to focus more on prevention as we did it in the past. To face new challenges it is good to work together with different partners, and sometimes you have to look back at what has already been done. That gives power for the future. I wish Saskia Weiß and her team and our board all the best!
A few words from Saskia Weiß, the new Executive Director of Deutsche Alzheimer Gesellschaft

My name is Saskia Weiß. I am 38 years old, a native of Berlin and the mother of two boys. During my social work studies, I did an internship at the Berlin Alzheimer Society. After my grandfather had dementia, I wanted to get to know the work of the association better.

I have been employed by the German Alzheimer’s Society (DAlzG) since 2008. I advised on our hotline – the “Alzheimer’s phone”, and accompanied various projects. Since 2016, I have been responsible for the “Demenz Partner” initiative, the German counterpart to the British Dementia Friends campaign.

Having served as Sabine Jansen’s deputy for the past four years, it was more or less obvious to follow in her footsteps and take over the role as Executive Director. Sabine Jansen developed the DAlzG into a strong and serious interest group over the past 24 years. Through her work and her personal commitment, she has made a significant contribution to the DAlzG being heard by political bodies and decision-makers. Together with my team, I would like to maintain this status for the association, always striving to improve the quality of life of people with dementia and their relatives.

For more information, visit: https://www.deutsche-alzheimer.de/ info@deutsche-alzheimer.de
The cost and burden of Alzheimer’s disease in Portugal

A recent study on the “Cost and burden of Alzheimer’s disease in Portugal” was conducted by Professor João Costa from the Center for Evidence Based Medicine (CEMBE). In this article, Alzheimer Portugal shares the details of the study and its findings.

A recent study on the “Cost and burden of Alzheimer’s disease in Portugal” was conducted by Professor João Costa from CEMBE – Center for Evidence Based Medicine (CEMBE is a structural unit of Lisbon School of Medicine created with the aim of spreading the principles of Evidence-Based Medicine).

The study is focused on people living with Alzheimer’s disease (excluding other different forms of dementia), aged 65 years old or more (not including people with early onset of dementia whose burden associated can be high) in mainland Portugal (excluding Madeira and Azores) during 2018.

Although some limitations are recognised in the study, its results characterise the socio-economic impact of Alzheimer’s disease based on the disease prevalence, and associated mortality and morbidity.

In our perspective, it shall be understood as a reference to the different stakeholders when designing strategies and policies to decrease the economic and social impact of Alzheimer’s disease in an aging population.

It is a meaningful contribution to the definition of priority areas, needs of resources, intervention plans or research within the health system.

Indeed, the study reveals some impressive figures: Alzheimer’s disease is responsible for 7% of the total of the years of life lost by premature death in Portugal. The premature death is responsible for 63% of the disease burden and the total burden associated to Alzheimer’s disease in 2018 was of 122,463 years of healthy life lost due to disability (disability-adjusted life years – DALYs) João Costa, MD and PhD, who coordinates the study states that “This total burden is more than five times higher in comparison to the total burden associated with heart failure (estimated by the same authors), another chronic clinical condition typically affecting older people with significant social burden.” (ref: https://pubmed.ncbi.nlm.nih.gov/30620150/)

In what concerns costs, society spends about EUR 2 billion (corresponding to about 1% of the Portuguese GDP) every year, on Alzheimer’s disease. Most of this goes on non-medical costs (about EUR 1.8 billion, including 1.1 billion on informal care and 551 million on social support). “The total Alzheimer-related costs are similar to the total societal costs of atherosclerosis in mainland Portugal, as estimated by the same authors in another study and using the same methodology. However, the estimated number of people with atherosclerosis is more than 7 times higher in comparison to the number of people living with Alzheimer’s disease”, claims João Costa. (ref: https://pubmed.ncbi.nlm.nih.gov/34274081/)

The informal care costs (54% of the total costs) were estimated according to the proxy good method approach that is based on the
time spent on caregiving at the labour market prices of a close market substitute, in this case the national minimum wage.

This estimation, being a very cautious approach to the cost of informal care, shows very well how important it is to create and implement measures allowing to reconcile work and family life, mainly for those who must leave work to care for a person with dementia.

The study, based on the number of people with Alzheimer’s attending health services or facilities, estimates that, in 2018, there were almost 100,000 (98,704) people with Alzheimer’s living at home with the support of an informal carer.

The study does not include an estimation of the loss of productivity when the carer leaves work to provide care full time, without paid employment. This perspective would be very useful to highlight the important role those informal caregivers play in the Portuguese society and would greatly help to stress that the legislation that regulates rights and duties and previews some measures to protect carers is not enough to recognise the value of caring, sometimes provided by neighbours and friends and not only by family members or by family caregivers.

Anyway, the “Cost and burden of Alzheimer’s disease in Portugal” study is a boost to highlight the urgent need of recognising dementia as a public health priority, needing to be urgently addressed.

According to Alzheimer Europe (Dementia in Europe Yearbook 2019 – Estimating the Prevalence of Dementia in Europe), it is estimated that in Portugal, in 2050, there will be 346,905 people living with Alzheimer’s disease or another form of dementia. This number will mean 3.82% of the Portuguese population.

Indeed, there is no time to lose as the number of people living with dementia will not stop increasing over the next decade. Therefore, it is key to establish strategies that may decrease the burden of disease, by delaying the natural evolution of Alzheimer’s disease through timely diagnosis, proper medical and social care and concrete measures of social support – to caregivers and others – considering these constitute the majority of cost calculated in the study.
Living (and hiking) with dementia: a message of hope and resilience from Stefan Eriksson and Janni Ahlgren

Stefan Eriksson, member of the European Working Group of People with Dementia (EWGPWD), was diagnosed with dementia at 50. He recently took a hiking trip with his daughter Janni Ahlgren (who supports him at EWGPWD meetings) and his brothers, Thomas and Anders, to climb Sweden’s tallest mountain, Kebnekaise. Janni recorded their trip on video, to share what the trip meant to them.

Stefan Eriksson has young-onset Alzheimer’s dementia. His eyesight was impacted by a car accident some 30 years ago, since which he has had double-vision. This has worsened with the progression of Alzheimer’s and has his ability to see colours and contrasts, and he has previously broken both his shoulders. Alzheimer’s has also made Stefan scared of heights. Despite these setbacks, he recently took a hiking trip with his daughter Janni Ahlgren and his brothers, Thomas and Anders, to climb Kebnekaise, Sweden’s tallest mountain, with an elevation of 2,103m. Reaching the summit had long been a dream of his.

Janni, a photographer with an interest in filmmaking, logged their trip on video and edited it into a ten-minute movie, which she has since shared on her YouTube channel. The movie shows what happened along the way and reflects on the purpose of the trip, as well as what both, she and her dad Stefan, were able to take from it.

With a little help...

As they approached the steeper side of the mountain, after hiking through some already difficult, rocky terrain, which was hard for Stefan with his eyesight problems, he began to panic. Janni helped her dad quell his fear by taking his hand and giving him a lot of positive encouragement and reassurance.

They struggled on together, later reaching a long footbridge over rapids. The structure of the bridge was metal mesh and the rushing water could be seen far below their feet which was very scary for Stefan. But again, with the support and encouragement of his daughter, he made it across. A proud moment for both of them!

After a long day of walking the rocky trail, they reached the mountain lodge, where they stayed for the night, and prepared themselves to climb the mountain the next day.

In my dad’s case, this was never about reaching the summit of a mountain, it was about challenging his fears, and seeing how far he could go with a little bit of help.”

Janni Ahlgren

Focusing on the positive

The climb started well, with just a bit of windy weather to contend with. Stefan used two Nordic walking sticks to help him keep his balance on the path and was coping really well, but after a while, the panic took hold of him again.

He and Janni decided to stop their climb and to leave Thomas and Anders to finish the rest of the climb to the summit without them, as they returned to the lodge.

Stefan tripped on many rocks along the way, but instead of complaining, he commented on how beautiful all the rocks were. Despite this positive mindset, he was disappointed not to have reached the summit and, in his own words, to have allowed his panic to stop him. Janni sees things differently, though. She was so proud of how far her dad had made it.
“In my dad’s case, this was never about reaching the summit of a mountain, it was about challenging his fears, and seeing how far he could go with a little bit of help”, she reflected.

**A message of hope and resilience**

Reaching the summit was not possible for Stefan on foot, but it was a dream of his for a long time, which Janni wanted to help him realise, no matter the means. Together with her uncles, she decided the four of them could reach the summit by helicopter.

Again, however, their efforts were thwarted, this time by cloud cover making it impossible for the chopper to land. And again, instead of feeling defeated they decided to enjoy the views and appreciate catching a glimpse of the summit from the air.

In the end, their trip was not exactly what they had aimed for, but the message of hope that Janni and Stefan took from this and which they want to share with others affected by dementia, is that by changing your thinking to see the positives and by focusing on what you can still achieve (sometimes with a little help), you can do amazing things. Even if you don’t quite make the target you were aiming for, with a bit of adaptability and some support, you can reach different goals and continue to live life to its fullest, whatever the circumstances.

Janni’s video, “Hiking Kebnekaise with my dad who has Alzheimer’s” is on her YouTube channel [https://www.youtube.com/watch?v=UdqYaKov38](https://www.youtube.com/watch?v=UdqYaKov38)

“By changing your thinking to see the positives and by focusing on what you can still achieve (sometimes with a little help), you can do amazing things. Even if you don’t quite make the target you were aiming for.”

*Stefan Eriksson*
The Davos Alzheimer’s Collaborative is one year old

Alzheimer Europe spoke to Drew Holzapfel, Founding Secretary of the Davos Alzheimer’s Collaborative (DAC), to find out more about the initiative and the work it has done in the year since its inception in January 2021.

Can you tell us a bit more about the Davos Alzheimer’s Collaborative, how it came into being and how it functions?

The idea for developing a global mechanism of action was first raised at the 2019 Lausanne Workshop. It was taken forward at the World Economic Forum’s Annual Meeting in 2020, where a diverse group of private-sector executives, government leaders and NGOs came together with a singular goal: How can we mount a global response to Alzheimer’s by orchestrating game-changing solutions to end the suffering, financial burden and stigma around this disease?

Alzheimer’s disease is a challenge that recognises no borders, so we knew that our solutions couldn’t either. That’s why the Davos Alzheimer’s Collaborative is mobilising a global partnership of leading, like-minded organisations to accelerate breakthroughs, develop and scale promising solutions and equip healthcare systems everywhere. Led by the World Economic Forum (WEF) and The Global CEO Initiative on Alzheimer’s Disease (CEOi), the DAC is investing over USD 700 million over six years to accelerate innovation in drug development and transform the way healthcare systems detect, diagnose and treat Alzheimer’s for all people in all regions.

To date, genetic research has focused overwhelmingly on white Europeans. As a result, we have an incomplete understanding of the heterogeneity of the disease. Better understanding of this will result in new therapeutic targets and precision medicine for Alzheimer’s disease. DAC is funding cohorts globally to make this possible. (see figure 1, p 34)

Alzheimer’s disease is a challenge that recognises no borders, so we knew that our solutions couldn’t either. That’s why the Davos Alzheimer’s Collaborative is mobilising a global partnership of leading, like-minded organisations to accelerate breakthroughs, develop and scale promising solutions and equip healthcare systems everywhere.”

The DAC was launched at the Davos World Economic Forum Meeting in January 2021. What are some milestones from this first year and what are the future goals?

2021 has been an exciting year for DAC. Most recently, we just concluded our USD 2 million request for locally-driven project proposals focused on early detection, and received over 70 responses from 21 countries (11 European countries), so we’re looking forward to driving the selected proposals forward in 2022. Other major achievements include:

• The completion of a cross-region, trans-ethnic Polygenic Risk Score pilot that engaged cohorts across the Middle East, Southeast Asia, Africa and South America.
• The securing of participation from 14 cohorts from around the globe.
• The development of a network of over 15 European sites for accelerating studies and implementing novel trial designs, with further opportunities identified across in Africa, East Asia, and Australia.
• The initiation of seven flagship projects in six countries focused on improving healthcare system capacity for early detection – including one in the UK.

DAC is looking forward to furthering its efforts and scaling its impact in 2022. Our activities will focus on:

• Completing our initial genome sequencing in the cohorts;
• Preparing 30 more clinical trial sites in the European Network;
• Hosting Learning Labs alongside major global health forums, including Lausanne IX and the World Health Assembly;
• Laying the groundwork for a flagship project focused on improving Alzheimer’s diagnosis.

The DAC has three main pillars; Global Cohorts, Global Clinical Trials and Healthcare System Preparedness. Can you tell us more about these and why they are focal points?

DAC’s three programmes respond to three key challenges to ending Alzheimer’s disease around the world:

• The Global Cohorts programme recognises the need to diversify data to unlock breakthroughs. Scientific discovery starts with high-quality data. But 90% of current genetic analysis comes from just 10% of the world’s population. DAC is building a global cohort of one million people who reflect the disease in all its global diversity to advance
understanding of Alzheimer’s among diverse populations. This data will provide the foundation for identifying new biomarkers and developing targeted treatments for people worldwide. In the foundational phase, DAC has engaged cohorts from 26 countries to diversify our understanding of Alzheimer’s and develop targeted treatments.

The Global Clinical Trials programme focuses on the value of linking together the best science to speed up innovation. Progress against Alzheimer’s requires faster, less costly clinical trials. DAC is building a global clinical trial network and a standing, trial-ready technology platform that will link trial sites around the world. This will drive innovation by reducing the time and cost of clinical trials, connecting researchers worldwide and accelerating drug development for people in all communities.

The Healthcare System Preparedness programme responds to the need to prepare today’s healthcare systems to deliver solutions to people everywhere. Innovations only make an impact if they reach the people who need them. DAC is investing in healthcare systems and solution providers to improve rates of early, accurate diagnosis and to ensure healthcare systems worldwide are prepared to deliver new innovations that enter the market.

The DAC has come into being during a global pandemic and public health crisis. Have these challenging circumstances impacted its first steps in any way?

Right now, governments are very focused on the immediate needs of COVID-19 relief, which is a critical effort. However, we need to make sure that we are not ignoring the slower-moving pandemic of Alzheimer’s disease, nor the individuals and families who are currently or who will in the future be impacted by Alzheimer’s disease.

“When it comes to health, the world has demonstrated a tendency to cycle through periods of neglect and panic,” said Dr David Bloom, Professor of Economics and Demography in the Department of Global Health and Population at the Harvard T.H. Chan School of Public Health, at our recent Lausanne workshop. “We neglect the issues when they’re not immediately imperiling us, then we scramble like mad when they’re in our face. Only to go back into neglect mode when they end. That was our experience with SARS, Ebola and – most recently and prominently – COVID-19. All I can say is: Shame on all of us if we repeat the experience with ADRDs” (Alzheimer’s disease and related dementias).

Innovations only make an impact if they reach the people who need them. DAC is investing in healthcare systems and solution providers to improve rates of early, accurate diagnosis and to ensure healthcare systems worldwide are prepared to deliver new innovations that enter the market.”
Ageing and dementia-friendly urban design

Edition 7 of the Journal of Urban Design and Mental Health had a special focus on ageing and dementia-friendly urban design. The journal is published online by the Centre for Urban Design and Mental Health, a global think tank and knowledge platform looking at how to better design cities to improve mental health. Alzheimer Europe spoke to guest editors, Daniel Gan and Zdravko Trivic, and to Helga Rohra, author of one of the papers included in the journal.

Edition 7 of the Journal of Urban Design and Mental Health focused on ageing and dementia-friendly urban design. What led to this focus?

Much of urban design research is about public life between buildings, which can be studied from multiple disciplinary perspectives. As public health scientists become increasingly interested in the social determinants of health and wellbeing, including neighbourhood effects and disparities, this edition attempted to bring together diverse approaches so that coherent frameworks may evolve to address the most pertinent issues, whether within or across disciplinary silos.

Daniel Gan caught sight of the gaps between disciplines through a systemic review of 29 articles, now published in The Gerontologist on dementia and the neighbourhood built environment (Gan, Chaudhury et al., 2021). As we appraised the diverse study foci and approaches, it became clear that brain health in community settings is an “interdisciplinary interdiscipline,” and a forum is required to chart the way forward. Zdravko Trivic, Assistant Professor of multi-sensory urban design and health who edited a special issue in Sustainability (MDPI), soon connected and began inviting contributions.

Why do you feel interdisciplinary approaches to dementia-friendly urban design is important?

Despite advancements within individual disciplines, gaps are evident in interdisciplinary dialogues on health-promoting environments. Crossing disciplines such that they enhance each other is required before we can identify all relevant mechanisms and translate empirical knowledge into successful evidence-based interventions and design.

Urban designers have a somewhat unfathomable concern about the quality of public life. When Daniel broached topics on neighbourhood ties in some public health circles, questions included: “Why should neighbours matter?” The answer hinges on our individual need for, or ability to perceive the meaning of public life. Numerous studies have shown that the neighbourhood functions as a psychosocial safety net and a social arena, especially when mobility becomes limited as older adults experience cognitive and sensory declines or other challenges. These spaces support social health of many older adults and their care partners.

Unless we place front and centre the actual experiences of older adults, designers may have a tendency to create imaginative worlds apart from the people we aim to serve, while public health scientists ignore the seemingly unimportant details that make up their realities. An understanding nod, or a way with words that dignifies and respects the other, these do come easily with public health interventions, but they can be carried by our interactions and project atmospheres. The solution is suffusing broad interventions with the humanity and poetry that are inherent in urban design. But meanwhile, urban designers must master and surpass current public health paradigms to ask new questions.

For Zdravko, this means framing interdisciplinary design research in ways that are translatable and helpful for design. Design thinking brings together different perspectives and evidences to generate solutions without disregarding intuition. Zdravko’s studio imparts and advances such design processes for health and wellbeing. Explorer student works were included in this edition.

Numerous studies have shown that the neighbourhood functions as a psychosocial safety net and a social arena, especially when mobility becomes limited as older adults experience cognitive and sensory declines or other challenges. These spaces support social health of many older adults and their care partners.”
Did you obtain inputs from people living with dementia and their care partners to inform these research directions?

Certainly. How can we re-humanise dementia research in the community unless we ourselves encounter the very persons our research professes to benefit? There is a global movement towards person-centred and community-engaged research. The research enterprise finds its legitimacy in answering relevant questions that potentially improve the wellbeing of taxpayers and the world we share. And what better ways are there to find potential solutions than to ask those with lived experiences?

It is a privilege to partner dementia self-advocates such as Jim Mann, LL.D., on various projects, and we are immensely thrilled that this edition established greater connections with scholars and patient partners across the Atlantic. There are now trans-Atlantic and trans-Pacific pilot projects led by several authors in this edition, and we are looking forward to fruitions from these collaborations. These partnerships are never easy, and we are ever thankful for the patience of older adults with and without dementia.

Your respective areas of research and expertise are quite different. Did you find it quite straightforward to mesh them together?

Bringing different areas of research and expertise together is never easy, and perhaps it should not be. It is through dialogue that we found exciting and fruitful convergence. This goes back to the plurality of research approaches in urban design. In many ways, plurality is and ought to be celebrated. We both have developed separately as scholars for some time. And while the education and research landscape changes with medical and technological advancements and aging populations, we find ourselves caught between the floodgates for creative solutions and rallying scholars toward a common goal.

As with all good designers, we pondered these tensions for some time and find the need to choose between them dissolving. It is not either-or but both-and. We hope the thrust of our editorial and the diversity of the articles reflected these, and we trust that public health scientists will find in urban designers and others — including the people we aim to serve — fresh and grounded ideas. Dual master programmes in Public Health and Urban Planning are but one indication of the demand for public health scientists that are well-versed in the lived realities of diverse populations. They remind us of how both of these professions shared common roots in 1800s Europe.

Our collaboration led an interdisciplinary study of effects of sensory environment and playfulness on depression and cognition among older adults, funded by the US National Academy of Sciences.

What are some of the main points to consider, when thinking about urban design for older people and people living with dementia?

A simplest but most impactful relearning comes from changing the word “for” in the question to “with.” We aspire not to designing spaces or policies “for” older adults and people living with dementia as if we understand what it is like to be old or to have dementia, or as if there is ever a blank canvas. Instead, we aspire to design and retrofit spaces, programmes and policies “with” them by first acknowledging that we do not know and want to know. This posture of humility and relearning is one of the reasons this work is hard but worthwhile.

One design does not fit all. The environment should rather have the built-in capacity to be flexible and customisable by different ages and ability groups for their needs. While catering to various vulnerable populations, designers should go beyond the deficit model and established universal design standards to reintroduce conviviality, holistic wellbeing, and interdependence by challenging and building different physical and mental abilities. This would not be possible without working closely with older people.

We would be remiss to leave out caution that age-friendly community or similar concepts are too often used by politicians to signal change and progress, especially if these projects are “photogenic.” At the end of the day, excellent sidewalks, clear signages, and a playful environment will be of no benefit to people living with dementia if others are not welcoming. While beautiful physical improvements may be welcomed by many, they are most likely to be accompanied by real change when they are celebratory by-products of meaningful community engagements.

Is there any advice you could give to policymakers aiming to improve the lives of people with dementia, through the medium of urban design?

Beyond basic access to quality housing and neighbourhoods which are still important public health goals in many cities, additional brick and mortar can only do so much. Funds for flashy projects, in which urban designers are sometimes complicit, will be better channelled to evidence-based neighbourhood improvement processes. We may start by inviting a community advisory board comprising older adults with and without dementia to put together an agile team of trusted community stakeholders, community development specialists, public health officers and urban designers, with co-leadership by trained facilitators and community-engaged researchers for systematic intervention development.

The systematic development processes are where public health research methods come in very handy. It will undoubtedly be difficult at first, but complex challenges such as creating communities that are accepting of the diverse socio-cognitive abilities of people living with dementia need both thinking, which is remarkably quite a designer(ly) trait. The specific goals should be set by community advisory boards. While actual interventions may differ from place to place, commonalities and transferable lessons should be drawn through case-comparative research to formalise engagement processes, and add psychosocial community dimensions (e.g., addressing stigma) to current planning best practices (e.g., Lewis, 2020, p. 26). Where appropriate, exploratory design research can test different design interventions in a participatory manner to save resources, e.g., before scaling up novel solutions for impact.
This edition of the Journal of Urban Design and Mental Health included a perspective paper called Wayfinding and Urban Design from the Perspective of People Living with Dementia – A Call for Participatory Research. As author of this paper, can you tell us a bit more about the importance of this topic, from your perspective as a person living with dementia?

From my perspective as a person living with dementia, and on behalf of the author team (Helga Rohra, Jim Mann, Mike Rommerskirch-Manietta, Martina Roes, and Saskia Kuliga), two topics of our research article are important:

First, we argue that people living with dementia would like to be included in research. In the article, we address why we feel this is important, and how this inclusion can take form. In brief, we feel that people may understand dementia, but they do not know what it is like to live with dementia every day. For instance, in co-authoring our research article, we continuously faced the question of meaningful engagement of people living with dementia in research, as well as stereotypes of individuals being perceived as vulnerable or incapable, even when we explicitly wish to share our perspectives.

Our paper is unique in the sense that we all relinquished some control in order to engage in co-learning from each other and to create the focus and content of this article together: as co-researchers and on eye-level.

Second, we argue that the topic of spatial orientation and wayfinding is important in the context of dementia, because disorientation is one of the early challenges people with Alzheimer’s disease face, and experiencing suboptimal environments can decrease our navigational confidence. Therefore, we would like to be included in providing feedback about planned or existing environments. For instance, urban designers, urban planners, architects and researchers who work on the topic of dementia-friendly environments could involve us. Our paper is unique in that we discuss various aspects that, from our perspective as people living with dementia, are important for orienting ourselves and for finding our way in cities: by keeping the focus solely on discussing the aspects that we, as people living with dementia, feel are relevant and meaningful in the context of wayfinding and urban design.

We seek to – both – inspire researchers and practitioners to include the diverse perspectives of people living with dementia in their projects, by asking and involving us; and also to encourage other people living with dementia to also raise their diverse voices and to engage in co-research about aspects that we find meaningful in our everyday lives and for living positively with dementia.

"We feel that people may understand dementia, but they do not know what it is like to live with dementia every day. For instance, in co-authoring our research article, we continuously faced the question of meaningful engagement of people living with dementia in research, as well as stereotypes of individuals being perceived as vulnerable or incapable, even when we explicitly wish to share our perspectives."
The Forget Me Nots Choir

The Forget Me Nots Dementia-Inclusive Community Choir

Baldoyle, North Dublin is a seniors choir and counts many people with memory loss conditions and their carers within its ranks. Founder Órla Horn tells us more about the choir’s beginnings, its achievements and how members have been adapting to COVID-19.

The Forget Me Nots is a dementia-inclusive community choir based in the beautiful coastal town of Baldoyle in North Dublin, Ireland. I founded it in 2014 with the help of two of my sisters – Fiona and Karen – inspired by our mother Kathleen Tierney – who loved music and had recently been diagnosed with Alzheimer’s disease at the age of 86. Her diagnosis came as a quite a shock to the family and we wanted to find things we could do with her to keep her happy and engaged. I heard about The Unforgettables Chorus of NYC featured on Irish radio which included dementia patients and their carers, and I thought what a wonderful thing to be able to do with Mam if I could only find the right choir! As it turned out, there was no such inclusive community-based choir, so I sought some starter funding from Fingal Arts Office, our local County Council, and with their support, and the enthusiastic help of local volunteers, we were off!

Involving the community and getting things started

Local children posted flyers into every household in the neighbourhood, and we started with a group of 11 (to include Mam’s dear friend Claire) – singing nostalgic songs our seniors could remember. The choir really took off with the appointment in 2015 of Norah Walsh, our Musical Director. Norah is a gifted musician and composer as well and brought the professional skills needed to create harmonies and arrangements for old songs to suit the different abilities within the choir – keeping aspects like old melodies accessible while introducing new harmonies, rhythms, mix of voices etc. to keep things challenging and interesting for everyone.

Another key element of the choir’s success is our group of amazing volunteers! Apart from their terrific operational support, they all love to sing and are mostly drawn from amateur women’s choirs in the area. This mix of vocal abilities from Soprano 1 to Alto 2 has given the choir security to stretch, while carers learn the harmonies if they choose and their loved ones with memory loss conditions can sing the melodies or hum or clap or even dance... whatever makes them happy and part of the group.

In 2016, we became a registered charity in Ireland, The Forget Me Nots Organisation, and now we have 150 members enrolled although the hall can only accommodate 110. We were able to maintain this safety limit through a rolling attendance of some nursing home residents and the ongoing need to people to attend medical appointments from time to time. Apart from professional musician fees, the choir is 100% supported by enthusiastic volunteers.

From strength to strength

The choir has gone from strength to strength in its first eight years! We have performed in every type of venue large and small (with the exception of a football stadium – although we were due to sing in Croke Park in Dublin until COVID-19 arrived!). This includes singing in local nursing homes for residents, in special rehab places like St Michael’s House and L’Arche, in key Dublin venues such as The Olympia Theatre, The Helix and The National Concert Hall with major Irish celebrities. We also love to sing in repeat venues such as The National Gallery for St Patrick’s Festival where we meet lots of foreign visitors, Fingal Atrium for the public at large, Dublin Airport at Christmas where we welcome arrivals from all parts of the world – all coming home for Christmas. In our neighbourhood, the ‘official’ start to Christmas is now when we sing in a local coffee house – Insomnia – where families can bring their kids to kneel in front of us and join in touching every part of our community and being touched by the hugely warm reception we get in return.

“This Shock of Flowers” – an anthem

Our choir continues to do amazing things... we’ve commissioned our own anthem composed by our Musical Director, Norah Constance Walsh, “This Shock of Flowers”. For inspiration, Norah surveyed our members to hear about what the choir means to us. The feedback was powerful! The choir brings us joy and happiness, it helps us express our emotions, it uplifts our mood, we’ve made new friends and feel we really belong in our community, we’ve even experienced fan mail, we’ve attracted sponsorship and support locally, nationally and from other countries to include Canada, Australia and the Netherlands! We’ve sung with visiting choirs from California, Texas and Virginia. We’ve recorded songs with household names such as Brendan Grace (RIP), Mike Hanrahan (Stockton’s Wing), Lisa Lambe, and Sandy Kelly. We’ve performed with Irish superstar Mike Denver, and Irish Showband celebrities like Philomena Begley and Brendan Shine. We’ve sung at the Áras for Irish President Michael D
Higgins and his wife Sabrina, and we’ve been touched by all the wonderful people we’ve met along the way.

**Before COVID-19**

Before the pandemic, we held a Grand Afternoon Tea Dance which became an annual event it proved so popular. Every week brought a new adventure and new invitation to perform. We featured on RTE radio with a documentary “A Song for Kathleen” and RTE television with Brendan Grace Rip – “Thanks for the Memories” which also featured a remembrance celebration concert in his honour at The Olympia. We have so many stories and new memories to mix with the yesteryears of our pasts. We celebrate birthdays and special events making a particular fuss of our 90-year olds!

We remember our deceased members by dedicating their favourite song in their memory. We retain members whose loved one has moved to residential care or who has died... the carers and family members are as much a part of our choir. No one knows, by looking at our members, who has a dementia condition and who doesn’t, and that’s the way it should be. We park all our troubles at the door of the hall and ensure the choir is a source of nothing but joy and comfort for each other. Because our volunteers help with the security of the harmonies and our seniors know all the old songs, we have tremendous fun exploring the challenge of learning new arrangements and new songs. We have an enviable male membership of about 40% and we all love the camaraderie and the craic that we have together every time we meet up – whether for rehearsals or the big performances! Our choir make-up is 30% people with memory loss conditions, 30% seniors and 30% carers/volunteers.

**Silver linings – coping with COVID-19**

Since “COVID-19” entered our daily lexicon (March 2020), we have not been able to meet physically to sing together. Our volunteers knew that we had to keep the choir going as it means so much to our members and they could slide back into social isolation very quickly. What to do? Well, we decided to create a Zoom session to replace our weekly Tuesday rehearsal and our volunteers worked with member families to get everyone zoomed in. Incredibly, within a week we had 80 seniors dialling into the call and we had so much fun together we decided to schedule a second zoom call on Fridays called “Silver Linings”. The
two calls are very different. On Tuesdays, we do warm-up exercises and learn new songs/harmonies for virtual singing projects. Norah plays for us on the piano and teaches us, while we’re on mute and sing back (all choirs know zoom doesn’t allow for harmonic singing due to voice compression over the internet). This works to a fashion. We also sing ‘party pieces’ for each other and love to recite poetry – something hugely valued in Ireland.

Since our ‘confinement’ we’ve managed to record three songs with another on the way:

- We’ll Meet Again
- A River Rolls On (written by Mike Hanrahan inspired by his mother – Mary Kelleher – who had vascular dementia. The song is a prayer to her spiritual life journey “from the mountains to the sea”. As it happened, Mary died within hours of its release – the last song she heard)
- Snowflakes (a Christmas song written by our member Gerry O’Halloran for his young children back in the 1970s. He sang it for us, we loved it and Norah composed harmonies and a musical arrangement with a professional score. Gerry and his family were thrilled, and we decided to record this together to celebrate his 90th birthday this year).
- We’re currently working on a climate change anthem which we plan to release next year – we’re recording this song virtually as well and to include children from the local schools, all fab stuff!

Our Friday Silver Lining sessions feature special guests who sing a particular musical genre or play a particular musical instrument while Norah covers musical appreciation around that theme. The range is limitless, and we’ve had repeat visits from amazingly talented guests of all ages and musical backgrounds. We’ve enjoyed Opera, Oboe, Classical, The Musicals, Frank Sinatra, Halloween, Christmas, Easter themes (and the list goes on)...add space endless fun and learning, and we thank our special guests with their favourite chosen poem recited by one of our amazing seniors.

Looking to the future

Where to next? Well, we just keep on keeping on with the help of our wonderful sponsors. We hope for the day we can return to the hall and the theatres performing together with all our hearts and in the meantime, we don’t let COVID-19 break our spirit. We’re grateful for technology – Zoom, WhatsApp, Facebook, Twitter, our website (see info box) which allows us to keep raising awareness about dementia conditions and the critical importance of families impacted by memory loss having a place in their community where they can participate in quality arts projects, tapping into what they can remember while being part of something new, vibrant, challenging and full of joy! Every community should have a dementia-inclusive community choir!

For more information, visit:
info@forgetmenots.ie
http://www.forgetmenots.ie/
ForgetMeNotsIE
@FMNChoir
@forgetmenotschoir
The Forget-Me-Nots Organisation

The choir performing at St Patrick’s Cathedral
31st Alzheimer Europe Conference takes place virtually

The 31st Alzheimer Europe Conference “Resilience in dementia: Moving beyond the COVID-19 pandemic” took place online from 29 November to 1 December 2021. Over 650 participants from 38 countries attended the event, which was Alzheimer Europe’s second virtual conference in the context of the global pandemic.

The 31st Alzheimer Europe Conference (#31AEC) “Resilience in dementia: Moving beyond the COVID-19 pandemic” was formally opened on the afternoon of 29 November 2021. Over 650 participants from 38 countries attended the event, which was Alzheimer Europe’s second virtual conference. On the agenda were almost 300 presenters (160 oral presentations, 137 quick oral presentations and 35 poster presentations), sharing their research, projects and experiences in an atmosphere of collaboration and solidarity.

All plenary sessions at the conference were co-moderated by conference co-hosts Kim Coppes from Live Online Events and Jean Georges, Executive Director of Alzheimer Europe. They began the event by welcoming delegates from the conference studio in Utrecht, Netherlands and gave the floor to Iva Holmerová, Chairperson of Alzheimer Europe, to officially open the conference.

European dementia community rises to the challenge of the pandemic

Iva Holmerová extended a special welcome to the 37 people with dementia who were among the delegates, as well as their supporters.

As was apparent during Alzheimer Europe’s first ever virtual conference in 2020, she noted, these conferences can be highly engaging and interactive, inviting delegates to make the most of the opportunities provided to ask questions to the presenters, give their comments and thoughts and to participate in the many polls and questions organised by Alzheimer Europe throughout.

When setting the theme for this year’s conference “Resilience in dementia: Moving beyond the COVID-19 pandemic”, Alzheimer Europe wanted to focus on how people with dementia, their carers, health and social care professionals, Alzheimer’s associations and the research community had adapted to the pandemic. “As Chairperson of Alzheimer Europe, I have truly been in awe at how the European dementia community has risen to the challenge of the pandemic and identified new and innovative ways to support, care and conduct research”, she stressed.

Iva Holmerová

In closing, she thanked the presenters and delegates for joining, the organising and programme committees and all conference sponsors, for making the event possible. In particular, she expressed her gratitude to the
health programme of the European Union and the corporate sponsors of the conference: AbbVie, ADDI the Alzheimer’s Disease Data Initiative, Biogen, Roche and TauRx Therapeutics. She also singled out the fantastic collaboration that Alzheimer Europe has developed with the INTERDEM network, which held its Annual Meeting just prior to the Virtual Conference and which was, as every year, strongly represented at this event.

Following these opening words, delegates were also welcomed by Chris Roberts, Chairperson of the European Working Group of People with Dementia (EWGPWD) and Marjolein de Vugt, Chairperson-elect of the INTERDEM network, followed by a video message from Hans Kluge, WHO Regional Director for Europe.

Promoting better quality of life for people with dementia and reducing dementia risk for the population

Chris Roberts addressed delegates from his perspective as a person living with dementia and as the Chairperson of the EWGPWD. He welcomed everyone to the conference and reflected on the importance of the EWGPWD and on how the group brings together people from different countries, giving an international voice to those living with dementia.

“Nothing About Us Without All of Us”, he reminded delegates, insisting that we all need to work together to promote a better quality of life for those affected by dementia and to help reduce the population’s risk of getting dementia. “We are doing our best to live with dementia, not dying from it”, he said and stressed that with support and understanding, people living with dementia can all live better lives.

INTERDEM highlights excellent collaboration with Alzheimer Europe

Marjolein de Vugt spoke on behalf of INTERDEM (Early detection and timely INTERvention in DEMentia). She highlighted that current circumstances challenge us; our resilience; our creativity and more than ever require our commitment to care.

WHO Europe says COVID-19 has caused a “seismic shift” in healthcare

In a pre-recorded video message to conference delegates, the WHO Regional Director for Europe Hans Kluge highlighted that dementia was the “leading cause of dependency and disability among older people in the WHO European region” and that WHO/Europe was therefore happy to have worked closely with Alzheimer Europe and other European partners on the implementation of the Global Action Plan on the public health response to dementia (2017–2025).

He added that “crises bring about change and COVID-19 is no exception. Systemic flaws in our health systems have been exposed”. For European countries, COVID-19 has been a “seismic shift in terms of healthcare” and for that reason, he called on delegates to identify good practices and learnings to improve the situation of people with dementia and their carers in Europe.

Resilience in dementia – adapting to the COVID-19 pandemic as a dementia advocate

The opening ceremony was followed by a short plenary session in which the first of two keynote presentations was delivered (the other took place on the last day of the conference). In his keynote presentation, which focused on resilience and adapting to the COVID-19 pandemic as a dementia advocate, Kevin Quaid, Vice-Chairperson of the EWGPWD, addressed the people with dementia in the audience.
Lessons from the COVID-19 pandemic

The second plenary of the conference was on “Lessons from the COVID-19 pandemic” and opened with a presentation on “Reinventing counselling and home support during the pandemic”, given by Jim Pearson, Director of Policy and Practice, Alzheimer Scotland and Board member and Honorary Secretary of Alzheimer Europe.

He began by noting that the disruption to daily routines, social interactions, and health and social care support during this pandemic has had a disproportionately negative impact on the physical and mental health of people with dementia and carers. He also noted that it is critical to have greater balance between public health measures in order to restrict the spread of COVID-19 and the harm we know those measures cause.

“We know what we need to do”, he stated. “People with dementia, their families and carers, need action now. They do not have time to wait for the lessons of this pandemic to be learned.”

During the next presentation, on “Protecting people with dementia in residential care – what we did right and what we got wrong!”, Pat McLoughlin, CEO, The Alzheimer Society of Ireland (ASI) noted that, whilst many countries have data that shows dementia was one of the main underlying conditions for deaths during COVID, there is no concrete information on the extent to which this is the case in Ireland.

He also stressed that the ASI felt that more could have been done by the Nursing Homes Expert Group or Government Special Committee to highlight the particular challenges faced by people with dementia during the pandemic. On the other hand, the ASI welcomed the practical measures and resources announced by the Government in home care supports and a more integrated community-based approach for people with dementia and their carers.

In the third and final presentation, Miia Kivipelto, Director of Research, Development, Education and Innovation, Karolinska University Hospital, Karolinska Institutet, discussed multimodal prevention studies and lifestyle changes during the pandemic. As the coordinator of the global World-Wide FINGERS network and the EURO-FINGERS project, she noted that the pandemic has had significant effects on many modifiable risk factors for dementia and Alzheimer’s disease, and on ongoing randomised clinical trials for dementia risk reduction and prevention. Negative effects of the pandemic include direct consequences of the COVID-19 disease, and indirect effects due to disruption of regular healthcare services, social and physical distancing or mobility restrictions imposed by several countries to curb the spread of the infection.

Innovations in dementia diagnosis and care through new technologies

The third plenary of the conference explored “Innovations in dementia diagnosis and care through new technologies”. Martin Traber, Global Medical Lead Alzheimer’s Disease, Roche, opened with a presentation on the importance of flexible care settings and home care management in clinical trials within a rapidly changing COVID-19 environment.

He said that the pandemic has highlighted the levels of inequality in healthcare systems, showing us how this had catastrophic effects in the dementia community and forced us to be more “pandemic prepared” for the future. “Flexibility will be fundamental to all future efforts to improve outcomes for people with Alzheimer’s disease, including how clinical trials are run and how patient care is delivered”, he stated.

Finally, he stressed that the responsibility of Roche had grown through their learnings around COVID-19, as well as when it comes to Alzheimer’s disease. According to him, partnerships and collaborations will be key to improving the readiness of healthcare systems worldwide.
Adrian Wagg, Professor of Healthy Ageing, Department of Medicine, University of Alberta, Canada discussed ways of improving continence care for nursing home residents, thanks to new technologies.

Urinary incontinence is common in people living with dementia and is a cause of considerable distress, he said, and yet it is often overlooked. It is a major contributor to care-partner distress and a significant contributor in decisions to institutionalise persons living with dementia, he stressed and noted also that the management of urinary incontinence is often suboptimal and there is great potential for improvement, using a number of promising technological solutions.

The third presentation of this plenary session was given by Petra Ritter, Johanna Quandt Professor for Brain Simulation at the Berlin Institute of Health, Charité University Medicine Berlin, Germany. She presented on “Augmenting diagnosis, inferring mechanisms, and predicting intervention outcomes in neurodegenerative disease through personalized VirtualBrainCloud simulations”.

Constructing and simulating individual models of the brain, or “digital twins”, is a powerful tool for innovation and personalised medicine, she said. These digital twins help us to understand mechanisms of brain function and dysfunction, which will allow us to develop measures for prevention and therapies.

The VirtualBrainCloud – a project of the European Open Science Cloud (EOSC) and a Partnering Project of the Human Brain Project and EBRAINS – provides a digital platform that enables collaborative research on sensitive health data in an audited environment that is compliant to the General Data Protection Regulations (GDPR) of the EU and thus protects the rights and the freedom of the data subjects and patients.

“The European Health Data Space will lift data-driven clinical research to a fundamentally new level”, she said, and in closing highlighted that they are working towards an ecosystem of interoperable health data infrastructures – co-designed by the research communities involved in this project.

Following this, an address was given to the delegates by Stella Kyriakides, European Commissioner for Health and Food Safety.

“To effectively meet the needs of dementia patients, we must first understand them. It is vital to reach out to them, their families as well as to informal carers, who make an incredible contribution to our communities every day”, she said.

“We are constantly learning about the human brain. Through its Framework Programmes for Research and Innovation, the EU will continue investing in effective prevention, better diagnostics and game changing treatments or cures. These will make a true difference for dementia patients across the Union”, she concluded.

Inclusive dementia care: the needs of the LGBTQ+ community

The third and final day of the conference opened with the second of two keynote presentations, which focused on inclusive dementia care and particularly on the needs of the LGBTQ+ community. Patrick Italo Ettenes, Co-founder of Bring Dementia Out, emphasised the importance of considering some of the real experiences of LGBTQ+ people living with dementia, noting that many organisations are still heteronormative and cis-oriented (cisgender/cissexual/cis describes a person whose gender identity is the same as their sex assigned at birth).

The need to be aware of issues around next of kin for LGBTQ+ people, who are often excluded from care decisions and who face fear of discrimination around their sexual and/or gender identities, was also highlighted.
Dementia as a public health challenge

The fourth plenary session focused on dementia as a public health challenge. Hana Marie Brouliková, Department of Health Sciences, Vrije Universiteit Amsterdam, and Coordinator of the national dementia strategy at the Czech Ministry of Health opened with a talk on “Keeping dementia as a health priority during the COVID-19 pandemic.”

A dementia strategy, she said, is more likely to be pursued when it is incorporated within wider public health policy. The Czech strategy is being implemented as part of a major reform of mental health care. She also stressed that, in order to effectively communicate and accommodate the needs of people with dementia and carers in crisis situations such as the ongoing pandemic, an advisory governmental committee consisting of a wide range of stakeholders is necessary.

Up next, Maria Teresa Ferretti, Co-founder and Chief Scientific Officer, Women’s Brain Project, Switzerland, examined the question of whether we are getting better at taking sex and gender differences into account in Alzheimer’s care. Sex (biological) and gender (socio-cultural) differences in Alzheimer’s disease are particularly relevant in the individual’s diagnostic pathway and medical journey, she noted. For example, she pointed out that of the 12 modifiable risk factors for dementia identified by the Lancet Commission in 2020, several are more common in women, including low level of education and depression.

“Considering sex- and gender-specific factors is a key step to improve access to and precision of diagnosis of Alzheimer’s disease”, she stated, noting also that a paradigm shift towards precision neurology would “optimize the diagnostic pathway and the individual’s medical journey.”

In the third presentation, Gill Livingston, Professor at University College London, explored preventable causes of dementia and their public health implications.

Worldwide, 40% of dementias may be preventable by addressing 12 risk factors, with half of that risk being accounted for by hearing loss, lower levels of education and smoking, she began. She highlighted that dementia risks cluster in people with fewer socioeconomic resources and in minority ethnic groups and stated that “the potential for prevention is high everywhere and particularly so in more deprived groups and in low and middle-income countries”.

Beyond the pandemic: Reinventing dementia care and treatment

The fifth and final plenary session took the form of a roundtable discussion called “Beyond the pandemic: Reinventing dementia care and treatment”. Participating in the discussion were Craig Ritchie, Director of the Edinburgh Centre for Dementia Prevention and Brain Health Scotland; Lutz Frölich, Head of the Department of Geriatric Psychiatry at the Central Institute for Mental Health in Mannheim and Chair of the European Alzheimer’s Disease Consortium; and Marjolein de Vugt, Professor at the Alzheimer Center Limburg, Maastricht UMC+.

Panellist Craig Ritchie drew attention to the fact that the COVID pandemic had illustrated continued challenges, with the priority (or lack thereof) given in health and social care systems to people living with dementia. Study set-up and delivery in platform trials has realised the value of platform trials, he said, but the months and even years we wait for study set-up is completely unacceptable.

He also highlighted that the pandemic shed some light on just how potent social isolation can be on cognitive decline and suggested that while digital and remote assessment could be a great complement to face-to-face meetings, they should never be a replacement for them.

During the discussion Lutz Frölich emphasised the need to put the wealth of scientific evidence that has been generated, into clinical practice. Drugs currently in development and undergoing evaluation by the European Medicines Agency (EMA) target the “proteinopathy” of Alzheimer’s disease, reducing amyloid plaques in the brain. They change the underlying biological process of the disease; however, the diagnostic process is highly complex and not all people who have mild cognitive impairment (MCI) would be eligible, he said.

On top of this, the process of proving the presence of amyloid, necessary to be eligible for this type of treatment, is burdensome on both patient and physician. Many things are still unclear including whether the EMA will approve the treatment for European countries at all. Other antibodies are currently in development, one or more of which may be approved in the coming years, he said, which would require some fairly important changes in medical systems. It is imperative that healthcare systems are prepared for this.

Marjolein de Vugt emphasised that a timely diagnosis can create opportunities for psychosocial prevention to improve the well-being of people with dementia and caregivers, while facing the daily social and
cognitive challenges of dementia. She also noted that an important future challenge in research is “to make dementia care increasingly precise and fully situated in a specific context at a specific point in time and to improve implementation of innovations in practice”. She pointed out that technological innovations such as e-health can help us advance such personalised approaches in dementia.

**Goodbye, virtual world. Hello, Bucharest!**

During the closing ceremony, delegates were invited to listen to a rendition of songs by the Irish Forget-Me-Not organisation which offers an inclusive community choir for older people and is especially welcoming to people affected by dementia. Norah Walsh, the Musical Director of the choir explained the history of the choir and how it had adapted to the pandemic by connecting and singing via Zoom and becoming a veritable lifeline for choir members. You can read more about the choir on pages 38-40.

The three-day virtual conference was formally closed by Alzheimer Europe Chairperson Iva Holmerová who thanked speakers and poster presenters for sharing their research, projects and experiences. She also said a special thank you to the various sponsors of the conference: The European Union Health Programme (2014–2020), AbbVie, ADDI the Alzheimer’s Disease Data Initiative, Biogen, Roche and TauRx Therapeutics.

All delegates were invited to mark the dates of the next Alzheimer Europe Conference (33AEC) in their calendars. “Building bridges” will take place in Bucharest, Romania from 17 to 19 October 2022.

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**See the difference with TENA**

TENA Pants have proven benefits that can make a real difference to the quality of life for individuals living with dementia and those that care for them. This is recognised in a study* in the UK where it says that the two most important benefits TENA Pants provides are skin integrity and comfort.

*C. Knifton, Selecting absorbent incontinence pads for people with Dementia, Nursing Times, May 2018;114 (5).

[www.tena.com](http://www.tena.com)
Seven special symposia held at #31AEC

Between 29 November and 1 December 2021, during the 31st Alzheimer Europe Conference (#31AEC), seven special symposia were held on a wide range of topics, including one by members of the European Working Group of People with Dementia.

European Working Group of People with Dementia: “Resilience and dementia”

One of the highlights of the virtual Alzheimer Europe Conference was a special symposium organised by the European Working Group of People with Dementia (EWGPWD). Three members of the group made videos for the symposium: Margaret McCallion from Scotland, Nigel Hullah from England and Erla Jónsdóttir from Iceland who was accompanied by her husband and supporter and Emil Emilsson.

The three speakers shared their views about resilience as part of living with dementia and also shared their experiences of living and coping with dementia during the pandemic, and how it affected them. A live question and answer session with the three speakers followed, moderated by Chris Roberts, Chairperson of the EWGPWD.

RECage project

This symposium was organised by the RECage project (REspectful CAring for the AGitated Elderly). This project aims at validating, adapting and upscaling the Special Care Unit for Behavioural disturbances of people with dementia (SCU-B). The first phase of RECage is a multicentre, prospective observational study aimed to assess the short- and long-term efficacy of the SCU-B. RECage started in January 2018 and will end on 30 December 2022.

Speakers were Sara Fascendini, who introduced the session and the project; Cristina Jori, who presented the RECage Clinical Trial; and Carlo Alberto Defanti, who shared the preliminary data on the concomitant qualitative study.

COVID-19 created serious problems during the follow-up period. An additional analysis, after the conclusion of the trial, will explore the effects of the pandemic on the trial results.

Building Resilience in Health Systems for People with: Early Detection and Timely Diagnosis in a COVID-19 World

This special symposium, organised by Roche, looked at why Alzheimer's disease (AD) continues to be undiagnosed or diagnosed too late, and how has this been exacerbated during the pandemic. It explored the impact of delayed detection and diagnosis of AD and asked how the care of people living with AD needs to change. It also asked whether the availability of disease-modifying therapies would change how we detect and diagnose AD, as well as how to ensure timely and appropriate diagnosis, treatment and care for people living with AD in a COVID-19 world.

The panel answering these questions consisted of experts from the AD community, including from primary care, secondary care, carer and industry. Questions for the panelists were posed by members of the EWGPWD.

Participants heard about how the detection and diagnosis of AD has been impacted by the pandemic, and discussed ways in which we can work together as an AD community, to develop solutions and move forward in a changing world.

The road behind and the road ahead: measuring the performance of 10 European governments on Alzheimer's disease

The Global Coalition on Aging’s (GCOA) organised this symposium, which featured insights and actions highlighted in the 2021 Alzheimer’s Innovation Readiness Index (AIRI). The comparative report evaluates how the governments and healthcare systems of 10 European countries are addressing prevention, diagnosis, treatment, and care for AD.
The Index, which was developed in partnership with Alzheimer's Disease International (ADI) and funded by Biogen, scores countries based on how they perform across five categories critical to sustaining AD efforts: strategy & commitment, early detection & diagnosis, access to care (medical), awareness & monitoring, care standards & settings.

During this session, attendees first heard from GCOA CEO Mike Hodin and from ADI CEO Paola Barbarino. Sagar Sane from GCOA then provided an overview of top line results and findings from the report.

GCOA CEO Mike Hodin moderated a panel discussion with expert contributors on some of the key findings and recommended actions for European leaders. These experts were Debbie Abrahams, MP for Oldham East and Saddleworth since 2011, and Co-Chair of the All-Party Parliamentary Group on Dementia (APPGD); Lorène Gilly from France Alzheimer; Pablo Martinez-Lage, Director of the Alzheimer's Disease Data Initiative and knowledge as well as data, to contextualise and extract more meaning from the data being shared.

**The Importance of Sharing Global Alzheimer’s Disease Data in Search of Novel Treatments and Cures**

This special symposium was organised by the Alzheimer’s Disease Data Initiative (ADDI) and was chaired by Tetsu Maruyama, Executive Director of ADDI. Panellists were Craig Ritchie (Professor of the Psychiatry of Aging, University of Edinburgh, UK) and Miia Kivipelto (Professor in Clinical Geriatrics at Karolinska Institutet, Sweden).

Opening the session, Tetsu Maruyama introduced ADDI, a medical research organisation bringing together a coalition of funding partners including pharmaceutical companies, academics and clinicians. Data sharing drives innovation and increases the utility of clinical research data, he explained, honouring the contributions of patients and research participants. However a major challenge is the fragmentation of data resources, which are often dispersed across different countries or sectors, as well as being siloed and hard to access. Addressing this is a key focus of the work of ADDI.

Next, Craig Ritchie highlighted the importance of data sharing globally and reminded the audience that the final EPAD (European Prevention of Alzheimer’s Dementia) dataset is available in the AD Workbench, to provide even greater value to the global neuroscience research community. Miia Kivipelto addressed questions around data sharing, highlighting that the starting point is about addressing why data is being shared, as well as looking data harmonisation as a way of ensuring the quality of the data. Miia closed the session by emphasising the value of sharing insights and knowledge as well as data, to contextualise and extract more meaning from the data being shared.

**The Importance of Brain Health and its impact on Alzheimer’s disease**

This Biogen symposium provided first-hand insights into how one of the most influential US patient advocacy organisations decided to approach brain health and stigma and built the Be Brain Powerful campaign, designed to change the behaviours of families, communities, policymakers and payers, to make brain health a priority, and to alter the trajectory of AD.

Delegates learned about the strategy and tactics that allowed this campaign to push brain health further up the public agenda. A range of topics were covered, including the importance of cutting through stigma, promoting equal access to brain health initiatives, and awareness around the benefits of early detection and diagnosis.

The meeting was moderated by Karin Hellsvik, Head of Corporate Affairs, Alzheimer’s Disease Business Unit at Biogen and presented by Kenny Brooks, Vice President, Consumer Engagement and Partnerships, UsAgainstAlzheimer’s.

**Late-stage clinical trial conduct during COVID-19: challenges, lessons, and the future for Alzheimer’s disease management**

TauRx launched a pivotal phase 3 clinical trial in AD in 2019 with top line results expected in mid-2022. During the trial recruitment phase much of the world was in some form of lockdown due to the COVID-19 pandemic. Despite this, the trial fully recruited swiftly. The pandemic presented various challenges to TauRx, the sites, the participants, and their study partners. Overcoming these challenges required flexibility and adaptability with many lessons learned along the way.

At the same time, GT Diagnostics, a joint venture between Genting Berhad and TauRx, forged ahead with its development of novel diagnostic tools targeting a diagnosis at very early stages of the disease. These tools are being developed with a view to eventually support remote administration, an important feature as further evidenced by the pandemic.

This symposium discussed the entire patient journey, ranging from the company’s vision of home-administered assessment and monitoring tools enabling access to treatment, whilst ensuring the safety of patients. The panel also explored how lessons learned from the trial, including the impact of COVID-19 on people with AD, and advances in diagnostics could translate into benefits in clinical practice.

The session was chaired by Serge Gauthier, Professor in the Departments of Neurology & Neurosurgery, Psychiatry, Medicine, at McGill University, and Director of the Alzheimer Disease and Related Disorders Research Unit of the McGill Center for Studies in Aging, Douglas Hospital.
Showcasing collaboration in European research initiatives at #31AEC

Neuronet – A coordination and support action bringing together 21 Innovative Medicines Initiative research projects on neurodegeneration, was strongly represented at the 31st Alzheimer Europe Conference (#31AEC).

Neuronet, a coordination and support action funded by the Innovative Medicines Initiative (IMI), brings together 21 IMI research projects working on neurodegenerative diseases such as Alzheimer’s, encompassing over EUR 386 million in research funding.

The Neuronet programme held four parallel sessions as part of the Alzheimer Europe conference on 29 November to 1 December 2021. The four sessions showcased patient and public involvement; common challenges & lessons learned from neurodegeneration research projects; how preclinical research can have a potential impact on people’s lives; and the impact and future perspectives for public-private partnership research on neurodegenerative disease.

The first parallel session was chaired by Dianne Gove from Alzheimer Europe. It was entitled “Elevating the patient voice: public involvement in Innovative Medicines Initiative neurodegeneration projects”. The four presentations in this session introduced the work of involving people affected by neurodegenerative conditions in IMI projects.

First, Ana Diaz (Alzheimer Europe) spoke about Alzheimer Europe’s work to promote Public Involvement in dementia research, for example via the creation of patient advisory panels in projects such as RADAR-AD and ROADMAP.

Stina Saunders (University of Edinburgh) and a member of the EPAD participant panel explained how their contributions led to the development of improved patient information materials and enhanced recruitment to the EPAD study.

After that, Johanna Graeber (University Medical Center Schleswig-Holstein) reflected on the patient involvement & engagement in IDEA-FAST, which is developing novel digital measures for fatigue and sleep disturbances.

The session closed with a presentation by Alison Keogh (University College Dublin), who described their roadmap of activity to develop patient and public involvement and engagement structures in Mobilise-D.

The second parallel session was chaired by Carlos Diaz from SYNAPSE, who is the Coordinator of Neuronet. The session revolved around “Collaboration and best practice: common challenges & lessons learned from the Innovative Medicines Initiative neurodegeneration portfolio”.

First, Lennert Steukers (Janssen) summarized the work done as part of the Neuronet data sharing working group, which identified several intertwined challenges that act as a barrier to data sharing.

Dalia Dawoud (NICE) then spoke about the development of the Regulatory & HTA decision tool, which guides users through the engagement process with these bodies during medicines development.

Angela Bradshaw (Alzheimer Europe) then explained how the Ethics and patient privacy working group is addressing key topics relating to ethics and data protection, looking to extract key learnings from the IMI portfolio projects.

Lewis Killin (SYNAPSE) was the final speaker of the session, addressing the concept of sustainability and extending the impact – and value – of research projects beyond the funded period.

The third session was chaired by Craig Ritchie, Director of the Centre for Dementia Research.
Prevention at Edinburgh University, and was entitled “From bench to bedside: preclinical research in Innovative Medicines Initiative neurodegeneration projects”. In this session, Shruti Desai (Radboud UMC) delivered a presentation about the quantification of mitochondrial morphofunction in neuronal cells, a topic that is being investigated within the PD-MitoQUANT project.

Next, Tania Fowke (MIMETAS) reported on the progress they have made with the neurovascular experimental model they developed in the ADAPTED project, showcasing how developments from closed projects can benefit new research initiatives. She explained that they are now using these models in the IM2PACT project, creating a model system where they can study the blood-brain barrier during stroke and in Alzheimer’s disease (collaborating with the Horizon 2020 projects ENTRAIN and CoSTREAM). Showcasing how developments from closed projects can be repurposed and developed further.

After that, Yang Shi (MRC Laboratory of Molecular Biology) introduced the most recent findings from the IMPRIND project about the structure-based classification of tauopathies and identification of PET ligand binding sites, a significant contribution to the field which was acknowledged as a front cover feature of Nature. The session closed with a presentation by Jannis Wißfeld (University Hospital Bonn) who presented about Alzheimer’s disease and PHAGO’s findings that a protective variant of CD33 increases microglial activation.

The fourth session was chaired by Lennert Steukers (Janssen), entitled “Looking to the future: Impact of the Innovative Medicines Initiative’s neurodegeneration portfolio”. It started with two presentations. The first, delivered by Fatima Salih of NICE, presented the outcomes of a series of stakeholder consultations held by Neuronet to assess gaps and priorities for neurodegeneration research. The second speaker, Carlos Diaz (SYNAPSE), focused on tools and assets developed by Neuronet itself, explaining how the NEURO Cohort, Knowledge Base and Asset Map could support ongoing and future research initiatives. This was then followed by a roundtable discussion involving representatives of a HTA/regulatory authority – Fatima Salih (NICE), an SME – Carlos Diaz (SYNAPSE), Industry – Laurent Pradier (SANOFI), Patient advocacy – Angela Bradshaw (Alzheimer Europe) as well as academia – Martin Hofmann-Apitius (Fraunhofer SCAI), bringing together the perspectives from a wide range of stakeholders to the table.

Acknowledgements

Neuronet has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 821513. The JU receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA and Parkinson’s UK.
#31AEC – A highly interactive conference

Our virtual conference was highly interactive, both on social media and via the hugely popular online polls we ran during plenary sessions. Here are a few highlights from the polls and from Twitter, as well as a few photos from behind the scenes at the conference studio in Utrecht.
### Facts and figures

<table>
<thead>
<tr>
<th>Country</th>
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<td><strong>Grand Total</strong></td>
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</table>

- **Academic or researcher**: 251
- **Alzheimer association staff or volunteer**: 159
- **Health or social care professional**: 71
- **Industry representative**: 38
- **Person with dementia**: 37
- **Student**: 34
- **Family carer**: 12
- **Civil Servant**: 10
- **Policy maker**: 8

97% of delegates would recommend future Alzheimer Europe Conferences to their colleagues.

97.7% of delegates rated the opening ceremony, keynote lectures, plenaries and closing ceremony of the conference to be good/very good.
Our members are helping people with dementia and their carers in 33 countries

Alzheimer Europe Members

AUSTRIA – VIENNA
Alzheimer Austria

BELGIUM – BRUSSELS
Ligue Nationale Alzheimer Liga

BULGARIA – SOFIA
Alzheimer Bulgaria

CYPRUS – NICOSIA
Cyprus Alzheimer’s Association and Related Dementias, Forget-Me-Not

CZECH REPUBLIC – PRAGUE
Czech Alzheimer’s Society

DENMARK – COPENHAGEN
Alzheimerforeningen

ESTONIA – TALLINN
NGO Living with Dementia

FINLAND – HELSINKI
Alzheimer Society of Finland (Muistillitto)

FRANCE – PARIS
France Alzheimer

GERMANY – BERLIN
Deutsche Alzheimer Gesellschaft e.V

GREECE – THESSALONIKI
Panhellenic Federation of Alzheimer’s Disease and Related Disorders

HUNGARY – BUDAPEST
Social Cluster Association

ICELAND – REYKJAVIK
Alzheimer Iceland

IRELAND – DUBLIN
The Alzheimer Society of Ireland

ISRAEL – KEFAR SABA
EMDA – The Alzheimer’s Association of Israel

ITALY – MILAN
Federazione Alzheimer Italia

ITALY – ROME
Alzheimer Uniti Onlus

JERSEY – ST HELIER
Dementia Jersey

LUXEMBOURG – LUXEMBOURG
Association Luxembourg Alzheimer

MALTA – MSIDA
Malta Dementia Society

MONTENEGRO – PODGORICA
NVO Futura

NETHERLANDS – AMERSFOORT
Alzheimer Nederland

NORWAY – OSLO
Nasjonalforeningen for folkehelsen

POLAND – WARSAW
Polskie Stowarzyszenie Pomocy Osobom z Chorobą Alzheimera

PORTUGAL – LISBON
Alzheimer Portugal

ROMANIA – BUCHAREST
Societatea Alzheimer Romania

SLOVAKIA – BRATISLAVA
Slovenská Alzheimerova spoločnosť

SLOVENIA – LJUBLJANA
Spominčica – Alzheimer Slovenija

SPAIN – MADRID
Fundación Alzheimer España

SPAIN – PAMPLONA
Confederación Española de Alzheimer (CEAFA)

SWEDEN – LUND
Alzheimer Sverige

SWEDEN – STOCKHOLM
Demensförbundet

SWITZERLAND – BERN
Association Alzheimer Suisse

TURKEY – ISTANBUL
Türkiye Alzheimer Derneği

UNITED KINGDOM – EDINBURGH
Alzheimer Scotland

UNITED KINGDOM – LONDON
Alzheimer’s Society
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Building bridges
Bucharest, Romania
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#32AEC