Bent Høie
Minister for Health and Care Services introduces Norway’s new Dementia Plan 2025

Chris Roberts
is the new Chairperson of the European Working Group of People with Dementia

Olivier Véran
Minister for Solidarity and Health outlines the future of dementia policy in France

Kim Coppes
Master of Ceremonies, moderates Alzheimer Europe’s first ever virtual conference
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It is a great pleasure to introduce the 35th edition of our Dementia in Europe magazine. As ever, we have endeavoured to fill it with interesting and useful updates on policy developments in the dementia field, campaigns and projects, among others.

The first section of the magazine looks at some of the key work our organisation has been involved in, over the past few months. The opening article recaps the European Parliament Workshop held online in December. We then move on to an overview of the suite of policy and ethics publications that Alzheimer Europe launched in the latter part of 2020. In the following article, we introduce the new European Working Group of People with Dementia (EWGPWD) and meet its members – we look forward to working with them during their term!

Turning to research projects in which Alzheimer Europe has been involved, the co-leads of the European Prevention of Alzheimer’s Disease (EPAD) project, Craig Ritchie and Serge Van der Geyten, reflect on the achievements of the project as it reaches its conclusion. We then hear from the leads of the recently-finished Patients Active in Research and Dialogues for an Improved Generation of Medicines (PARADIGM) project, Nicola Bedlington and Magda Chlebus. A brief update on the progress of the Neuronet Knowledge Base follows and finally, we hear from Charlotte van Corven about the SPAN+ project, which focuses on empowering people with dementia.

In the Policy Watch section, we are delighted to have an interview with the Norwegian Minister for Health and Care Services, Bent Høie, who introduces the country’s new dementia strategy, whilst Secretary General for the Norwegian Health Association (Nasjonalforeningen for folkehelsen), Mina Gerhardsen, shares her reflections on this important development. We are then pleased to present an interview with French Minister for Solidarity and Health, Olivier Véran, who outlines the future of dementia policy in France, with President of France Alzheimer, Joël Jaouen, providing his organisation’s perspective. Staying at the national level, Avril Easton from The Alzheimer Society of Ireland discusses the organisation’s campaign in the lead-up to the Irish budget and shares their success in securing additional funding for dementia services.

At a European level, Alzheimer Europe presents some of the latest developments in EU policy, examining the future budget of the EU and the implications for health and research policies. In addition, we summarise the latest meeting of the European Group of Governmental Experts on Dementia, which met online in December 2020, to discuss recent dementia policy developments across Europe.

The Dementia in Society section opens with a focus on COVID-19, with members of the EWGPWD writing about how the measures to control the spread of the virus have affected them. This is followed by an article in which our member associations outline how the human rights of people with dementia and their carers have been affected during the pandemic, in their respective countries.

As part of our work supported by Gates Ventures, Alzheimer Europe Project Officer Angela Bradshaw shares insights into the perspectives of research participants and patients, on data sharing, highlighting some of their key concerns. Following this, Alzheimer Europe spoke to six early stage researchers (ESRs) working on two EU-funded research projects, to gain a better understanding of what drew them to the field of dementia research and to ask how COVID is affecting their work. We then go “Behind the Headlines”, with Alzheimer Europe Project Officer Cindy Birck and Tobias Hartmann of the European LipiDiDiet project, to examine the effect of a multinutrient intervention (Souvenaid) on cognitive and functional decline in early Alzheimer’s disease.

The last article in this section is our “Dementia in the Arts” feature in which we speak to Gina Martin, Founder and Executive Director of the Bob and Diane Fund, who shares her motivation for creating this annual photography award for visual storytelling about Alzheimer’s and dementia. She also discusses the winning project for 2020.

To round off this edition of the magazine, we take a look back at the 30th Alzheimer Europe Conference (30AEC), which was held virtually for the very first time, in October 2020. The event was co-moderated by Kim Coppes from Live Online Events and Jean Georges, Executive Director of Alzheimer Europe. Despite the unusual circumstances, the conference was a great success, with almost 800 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 those organised by the EWGPWD, and the Neuronet and VirtualBrainCloud projects.

As we head into 2021, I wish you good health and a prosperous and safe new year! Happy reading!
Alzheimer Europe hosts workshop focusing on maintaining dementia as a policy priority during the COVID-19 pandemic

Alzheimer Europe organised a European Parliament Workshop, hosted by Sirpa Pietikäinen, MEP, to discuss how people with dementia had been affected by the pandemic and the importance of maintaining dementia as a policy and research priority.

Alzheimer Europe held an online European Parliament Workshop on 9 December 2020, examining dementia in the context of the ongoing COVID-19 pandemic. Hosted by Sirpa Pietikäinen, MEP (Finland), Chairperson of the European Alzheimer’s Alliance (EAA), the workshop included presentations from Alzheimer Europe staff and European Commission representatives, as well as contributions from EAA Vice-Chairperson Deirdre Clune (EPP, Ireland) and EAA member Marc Angel (S&D, Luxembourg).

The event was also attended by EU policymakers, representatives from national Alzheimer’s associations and national health ministries, pharmaceutical companies and members of the European Working Group of People with Dementia (EWGPWD).

The impact of COVID-19 on people living with dementia

Dianne Gove, Director for Projects, Alzheimer Europe, presented information on how the COVID-19 pandemic has negatively affected people with dementia and their communities, explaining that this population had been some of the most severely affected. She highlighted the fact that some in some EU countries, between 20–30% of COVID-19 deaths have been in people with dementia.

It was further explained to attendees that some people with dementia have experienced an increase in feelings of loneliness and confusion, as well as a deterioration in symptoms, as a result of some of the measures introduced (e.g. shielding, lockdown measures etc.). In addition, the negative impact of losing daily routines and contact with family and friends, was highlighted as placing people with dementia at greater risk for self-neglect and risk, especially where health and social care interventions had been curtailed as a result of the pandemic.

Healthcare systems’ response to the pandemic

Angela Bradshaw, Project Officer, Alzheimer Europe, provided an overview of how health and social care systems have been stretched during the pandemic. Examples were provided of the extraordinary measures which countries across the EU have taken in the extenuating circumstances created by the pandemic, including the cancellation of supports and services, the use of retired clinical staff to support increase system capacity, as well as the adaptation of standard wards into COVID-19 intensive care units.

It was explained that such approaches have required additional investments from central governments, which has been examined by the “Health at a Glance: Europe 2020” report published by the Organisation for Economic Co-operation and Development (OECD) and the European Commission.

In addition, many national Alzheimer’s Associations made considerable efforts to continue their support of people with dementia, providing online services and helplines as well as accessible resources and guidance, often quickly innovating to find new ways to support individuals, particularly where in-person supports were not possible. Furthermore, the negative effects on dementia research were outlined, including the closure of research laboratories and the cessation or delay of numerous clinical studies, as well as some early-career researchers considering leaving dementia research, with concerns that this dementia research will be deprioritised in favour of infectious diseases research.

Alzheimer Europe launches a new policy report

Owen Miller, Policy Officer, Alzheimer Europe, introduced the Alzheimer Europe policy report, “Dementia as a European Priority – a Policy Overview”, which sets out the position of dementia as a policy priority, primarily at the European level. The report outlines some of the key developments and initiatives in recent years, including actions taken by the European Commission, the Council and Parliament (including the Joint Actions on Dementia, dedicated funding for dementia research etc).

It was explained to attendees that in addition to the recap of previous measures, the report outlined key recommendations both for national and EU level policy and decision makers, which would form the basis of Alzheimer Europe’s public affairs work in the near future, centred around health, social, research
and human rights policies. These had been developed in response to the current context at the EU but also as a response to engagement with its members at a national level, as well as other stakeholders.

Key recommendations include the need for dementia research to be prioritised in EU research programmes such as Horizon Europe, the need for dementia to be included within key EU programmes such as the EU4Health programmes and the forthcoming green paper on ageing, as well as the importance of countries signing and ratifying international treaties on rights, such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The future of dementia policy and research at an EU level

Isidro Laso Ballesteros, Cabinet Expert for Mariya Gabriel (EU Commissioner for Innovation, Research, Culture, Education and Youth) spoke about dementia as a priority of the current and future research programmes of the EU, highlighting the breadth of dementia research that has been funded by Horizon 2020. In particular, he highlighted the work undertaken through the Innovative Medicines Initiative (IMI) partnerships and the Joint Partnership on Neurodegenerative Diseases Research (JPND) for the work funded to develop new diagnostics, tools and treatments for dementia.

A high-level overview of the future Horizon Europe research programme was provided, with specific attention drawn to the increased funding for the future which had been made available for the programme, as well as some of the future opportunities within it for dementia research. These included the dedicated health cluster of pillar 2 of the programme (Global Challenges and European Industrial Competitiveness), as well as the proposed successor to the IMI partnerships (the European Partnership for Innovative Health), the details of which have yet to be finalised.

The last speaker, Stefan Schreck, Adviser to the European Commission Health & Food Safety Directorate General, recapped some of key areas of work that the EU had supported in relation to dementia in recent years through the current Health Programme, including the Joint Actions on Dementia, as well as direct support for the work of Alzheimer Europe through the Operating Grant. It was explained to the attendees that the proposed EU4Health programme and the substantial increase in the budgetary allocation within the Multiannual Financial Framework (MFF) will provide opportunities to strengthen health systems and promote best practice, providing a route for dementia to be addressed as a priority for the EU. Additionally, it was highlighted that the priorities of the new programme would reflect the issues and priorities outlined by Member States.

Drawing the workshop to a close, Sirpa Pietikäinen, MEP (Finland) moderated a question and answer session, during which participants asked speakers for further details, particularly in the relation to the future EU4Health and emphasising that the 95 members of the EAA will continue advocating for people with dementia and their carers at EU level.

The next online European Parliament Workshop is expected to take place on 23 February 2021, focused on the use of data in dementia research across Europe.
Alzheimer Europe has published four reports, examining issues of dementia policy, practice and ethics, at a national and European level.

Despite the COVID-19 pandemic, Alzheimer Europe continued working throughout 2020 to generate knowledge and evidence to inform policy and decision-makers, identifying the key areas which must be addressed to improve the lives of people living with dementia. In 2020 Alzheimer Europe launched four reports examining dementia policy, practice and ethical issues at a national and European level.

Intercultural dementia care for health and social care providers: a guide

Following on from its 2018 report on “The development of intercultural care and support for people with dementia from minority ethnic groups”, Alzheimer Europe has responded to this challenge by developing, with a group of experts, a guide to support health and social care workers to provide intercultural dementia care and a policy briefing containing guidelines for policy makers.

The key principle underpinning this work is that every person with dementia should be aware of, and have access to, culturally appropriate dementia care. It is reiterated within the guide that health and social care workers must recognise that every person with dementia is unique; although people with dementia may share some characteristics with other people from a particular ethnic group, it is essential to recognise the individuality of every person.

The number of people with dementia from minority ethnic groups is increasing, partially as a result of migrant populations in Europe ageing and some ethnic groups being a higher risk of developing dementia. Although many symptoms of dementia can be managed with good care, the uptake of dementia care services by people from minority ethnic communities remains low.

Within the new guide, a number of recommendations are made, including encouraging health and social care workers:

- To provide people from different ethnic communities with culturally appropriate and understandable information about dementia and existing services and support
- To make sure that people understand that dementia is a medical condition and that health and social care systems in Europe offer support and care to people with dementia and their families
- To explore the kind of support or services that would be helpful, adapt existing supports if necessary and develop new innovative approaches that reflect the needs and wishes of people from different ethnic communities
- To develop cultural awareness, sensitivity and competence through an ongoing process of learning and exchange between and amongst health and social care workers and people from minority ethnic group.

Dementia as a European Priority – A policy overview

In December, Alzheimer Europe launched its report “Dementia as a European Priority – A policy overview” which takes stock of dementia policy at an EU level and sets out recommendations for future priorities across Europe.

As the European Union moves towards implementation of the EU4Health and Horizon Europe programmes, Alzheimer Europe reflects on the place of dementia as a political priority in Europe in recent years. This includes the different ways in which dementia policy and research have been supported by the three institutions of the EU, as well as some of the high-profile coordination and research projects which have been made possible as a result of EU funding.

In the report, Alzheimer Europe also highlights some of its key activities in campaigning for change, as well as the work it has coordinated and participated in, along with its national member associations, to raise the profile of the condition and build an evidence base to make the case for the prioritisation of dementia.

Despite the progress made and the knowledge generated, the report highlights that people living with dementia continue to face a number of challenges. These challenges, which concern wider society too, include the increase in the number of people living with dementia (estimated to double by 2050) and the societal and economic cost of dementia.

As a result, the report sets out a number of recommendations for the EU, outlining specific areas in which dementia should be prioritised across international, health, research and social policy, including:

- Prioritising dementia research in EU Research Programmes (including Horizon Europe), providing a fair allocation of resources and funding for existing programmes and better coordination between programmes
- Prioritising dementia within policies relating to chronic diseases, mental health and ageing, both at an EU and national level
- Supporting Member States to work towards the implementation of the World Health Organization’s Global Action Plan on Dementia 2017–2025
- Recognising dementia as a disability and including dementia in disability policies.

The full report can be accessed at: https://bit.ly/DementiaEUPolicyOverview2020-online

Ethics report on legal capacity

In its most recent ethics report, Alzheimer Europe1 explores some of the ethical issues linked to legal capacity and decision making. Legislation and guidelines contribute towards but do not guarantee ethical behaviour. They do not protect everyone’s rights or ensure that everyone has the same opportunities. Any loss of the right to make decisions can have a considerable impact on people’s lives and wellbeing.

Being formally and publicly declared as having no or limited legal capacity may have a devastating psychological, emotional and practical impact. For some people, it is experienced as an affront to their dignity, affecting their personal relationships with other people and their standing in the community. Legal capacity is therefore a legal concept but it is not just a legal matter. Legal capacity and decision-making capacity are interrelated and have social and ethical implications.

This is why it is important to reflect on ethical issues directly or indirectly linked to the concept of legal capacity. This includes respect for human rights, which means recognising and protecting the dignity of all human beings, and ensuring that everyone is entitled to active, free and meaningful participation in, contribution to, and enjoyment of civil, political, economic, social and cultural

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1 Authors: Dianne Gove, Carmel Geoghegan, Jean Georges, Alistair Neimeijer, Jim Pearson, Catherine Quinn, Sebastian Ritzi, Helen Rochford-Brennan, Matthé Scholten and Maria do Rosário Zincke dos Reis.
development. The report contains a detailed discussion and recommendations for each of the following topics:

- Guardianship
- Treatment, care and support
- Communication of the diagnosis
- Advanced care planning and advance directives
- Participation in research
- Coercive measures
- Restrictions of freedom and the use of restraint during the COVID-19 pandemic
- Voting, marriage and civil partnerships, and making a will.

Members of society need to work together to remove obstacles, whether they be legal or based on mentalities, traditions or taken-for-granted, limiting assumptions. This is a task for everyone not just for lawmakers, policy makers, health and social care professionals and notaries. Not everyone has the power to bring about change directly, but everyone has the power to raise issues and challenge practices, procedures and attitudes. We hope that this report will be successful in raising awareness about the many issues related to legal capacity and decision making in the context of dementia and thereby contribute towards improving the lives and wellbeing of people with dementia.

The full report will be available in March 2021, on the Alzheimer Europe website: https://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports

Dementia Monitor 2020

In 2017, Alzheimer Europe published its first Dementia Monitor report, providing a benchmark and indicators for the current state of dementia policy across the EU and countries in which we have member associations, in relation to the following areas:

- Care aspects
  - Availability of care services
  - Affordability of care services
- Medical and research aspects
  - Treatment-reimbursement of AD medicines
  - Availability of clinical trials
  - Involvement of country in European dementia research initiatives
- Policy issues
  - Recognition of dementia as a priority
  - Dementia friendly communities/inclusiveness
- Human rights and legal aspects
  - Recognition of legal rights
  - Ratification of International and European human rights treaties
  - Carer and employment support.

Alzheimer Europe repeated the exercise across 2019 and 2020, gathering information with the support of our members, allowing not only for the creation of a snapshot of the current situation, but also to understand how the situation has evolved over recent years.

For the majority of services (that we enquired about), there has been an increase in the number of countries reporting that they are sufficiently available, however, a majority of countries continues to report that most services are insufficiently available or absent. In relation to the funding of services, the majority of services continue to be funded (at least in part) in the majority of countries, with the majority of services showed an increase in the number of countries providing some level of funding.

In relation to policy, 27 countries have a national dementia strategy (with Flanders having its own strategy, and separate strategies for England and Scotland in the United Kingdom), compared with 21 countries in 2017, however, fewer than 50% of countries reported that funding had been put in place to implement the strategies or had a dedicated lead person within the government to lead the response.

An increasing number of countries are taking part in European coordinated programmes – on 2019 there were 29 countries involved in the funding call, however, at the close of 2019, almost 50% countries were unable to take part in a clinical trial related to dementia.

The full report will be available in March 2021, on the Alzheimer Europe website: https://www.alzheimer-europe.org/Publications/Alzheimer-Europe-Reports
European Working Group of People with Dementia begins fifth term of office

The European Working Group of People with Dementia began its fifth two-year term of office at an online meeting on 23 October 2020 and welcomed four new members.

Members: Idalina Aguiar, Portugal; Stefan Eriksson, Sweden; Tomaž Gržinič, Slovenia; Nigel Hullah, UK – England, Wales and Northern Ireland (new); Petri Lampinen, Finland; Margaret McCallion UK – Scotland (new); Danny McDonald, UK – Scotland (new); Erla Jónsdóttir, Iceland (new); Angela Pototschnigg, Austria; Helen Rochford-Brennan, Ireland; Geert Van Laer, Belgium.

The group was launched by Alzheimer Europe and its member associations in 2012 and is composed entirely of people with dementia who are nominated by their national Alzheimer associations. They work to ensure that the activities, projects and meetings of Alzheimer Europe duly reflect the priorities and views of people with dementia. They also consult on EU-funded research projects. The group operates independently and members elect their own Chairperson and Vice-Chairpersons. The Chairperson is also an ex-officio member on the Board of Alzheimer Europe, with full voting rights.

During the group’s first four terms of office (2012–2014, 2014–2016, 2016–2018, 2018–2020), members have actively participated in Alzheimer Europe’s annual conferences and contributed to research conducted by external organisations on topics such as: meaningful outcome measures; social health; people with dementia as peer-researchers, palliative care and data sharing as research participants and in the context of Public Involvement; helped develop recommendations on dementia-inclusive initiatives and contributed towards Alzheimer Europe’s work on various ethical issues. They have also attended a number of international dementia-related events, including at the European Parliament, as representatives of the group.

For more information about the group, visit: https://www.bit.ly/EWGPWD

The members

Idalina Aguiar
Country: Portugal
Diagnosis (type and year): Alzheimer’s dementia, 2012
Joined the group: 2016
A bit about me: I was born in 1940, in Madeira. My work gave me the opportunity to travel, which I enjoy. I also like to sing, dance, play cards, do crosswords, read and garden. My daughter (and carer) Nélida and I believe that a balance between drugs and complementary therapies is ideal in dementia, so I do a variety of different therapies. We also work to combat stigma, and fight for the rights of informal carers in Portugal.

Stefan Eriksson
Country: Sweden
Diagnosis (type and year): Alzheimer’s dementia, 2017
Joined the group: 2018
A bit about me: I am from a small island called Kalvsund, just outside Gothenburg. I spent many years working on power plants around the world, mostly in the US, Sweden and Africa. I have always been active in sports and I still like to go to the gym. Since being diagnosed, I have also started doing gardening and enjoying more time outdoors.

Tomaž Gržinič
Country: Slovenia
Diagnosis (type and year): Alzheimer’s dementia, 2016
Joined the group: 2017
A bit about me: I was born in Ljubljana in 1952 and spent most of my career at a well-known Slovenian graphic design company. I am very active, with a special interest in sailing, and in the summer, I go on sailing holidays with a close group of friends. Support from my closest family and friends plays a major role in my everyday life.

Bernd Heise (Vice-Chairperson)
Country: Germany
Diagnosis (type and year): Alzheimer’s dementia, 2016
Joined the group: 2018
A bit about me: I am married and live in Munich with my wife. For 34 years, I worked as a development engineer of semiconductor devices in the telecommunications industry, until my diagnosis. I am also a member of the Advisory Board of People Living with Dementia, founded by the German Alzheimer association (Deutsche Alzheimer Gesellschaft). My favourite hobbies are gardening and computer technology.

Nigel Hullah
Country: United Kingdom (Wales)
Diagnosis (type and year): Early-onset dementia, 2012
Joined the group: 2020 (new member)
A bit about me: I have a lot of experience of working with groups at a regional and national level. I have gained exposure to the development of services and helping with innovation of strategies. I have supported the rights of all disabled people (including those with a dementia diagnosis) for equitable services, the fulfilment of statutory and civil rights and the promotion of their preferences and a right to be heard.

Petri Lampinen  
Country: Finland  
Diagnosis (type and year): Fronto temporal dementia, 2015  
Joined the group: 2017  
A bit about me: I refuse to let the difficulties associated with my dementia defeat me, and in spite of them, I continue to live an active life, working in my garden, cycling and playing ping-pong and badminton. Being open about my condition and remaining as calm as possible in any situation helps me navigate life with dementia, with the support of others when needed.

Margaret McCallion  
Country: United Kingdom (Scotland)  
Diagnosis (type and year): Young-onset frontotemporal dementia, 2016  
Joined the group: 2020 (new member)  
A bit about me: I live in Glasgow and am a member of the Scottish Dementia Working Group (SDWG) as well as the EWGPWD. My diagnosis was a shock and my consultant suggested I go to a new resource centre. I had reservations about it, but was pleasantly surprised at the warm welcome I received and the support. I am thankful I keep good health and have great support from my family, friends, religion and Alzheimer Scotland!

Danny McDonald  
Country: United Kingdom (Scotland)  
Diagnosis (type and year): Vascular dementia, 2016  
Joined the group: 2020 (new member)  
A bit about me: I live in Clydebank, just outside Glasgow, Scotland. I am married with two grown up children. Since my diagnosis, my family and I have learned that it is possible to live well with dementia. I am involved in many activities from day centre to choir and, as a family, we enjoy taking part in quiz nights.

Angela Pototschnigg  
Country: Austria  
Diagnosis (type): Alzheimer’s dementia, 2020  
Joined the group: 2018  
A bit about me: I have been living with cognitive impairments for 6 years. The path to a valid diagnosis took a long time: At first, burnout was wrongly diagnosed. I am an ambassador for inclusion and the rights of people with dementia. I hold peer-talks twice a month, organised and supported by Alzheimer Austria, aiming to reach others who are worried about their memory or have received a diagnosis of dementia and want to talk. I also represent people with dementia on committees working on the Austrian Dementia Strategy and the upcoming care reform; give talks to carers, in dementia-friendly communities; and I engage in various projects that focus on participation of and information about people living with dementia. These activities help to give my life meaning.

Kevin Quaid (Vice-Chairperson)  
Country: Ireland  
Diagnosis (type and year): Lewy body dementia, 2017  
Joined the group: 2020 (new member)  
A bit about me: I am a Limerick native, but now live in Cork with my wife, Helena. I have three children, three stepchildren and five grandchildren. As well as a family man I am an adventurer and love to travel. I am also an avid GAA (Gaelic football) fan. Community is important to me and I started a Memory Café in Kanturk, where I live, to support others like me, in my area. I have written a book called “Lewy Body Dementia Survival and Me” and am one of the first people in the world to write a book about Lewy body dementia (LBD) from the patient’s point of view. I am currently working on my second book on how to live a productive life after a diagnosis. I also write for a local newspaper and I never knew that I had a love for writing until I was diagnosed with LBD!

Chris Roberts (Chairperson)  
Country: United Kingdom (Wales)  
Diagnosis (type and year): Mixed dementia (Alzheimer’s and vascular), 2012  
Joined the group: 2016  
A bit about me: I spend most of my time raising awareness of dementia, to dispel the associated stigma. To promote the development and continuation of better services and support, I campaign to uphold the rights of all affected by dementia. When I speak at events either in Wales, the UK, or Europe, I am usually accompanied by my wife, Jane Goodrick.

Helen Rochford-Brennan  
Country: Ireland  
Diagnosis (type and year): Alzheimer’s dementia, 2012  
Joined the group: 2014  
A bit about me: I was Vice-Chairperson of the EWGPWD for two years (2014–2016) and Chairperson for four (2016–2020), stepping down in October 2020, but am delighted to stay on in the group. I use my time with the working group to raise awareness of dementia and raise the profile of human rights for people with dementia. Previously, I spent many years working in the tourism and disability sectors and was involved in community activism.
**Geert Van Laer**  
**Country:** Belgium  
**Diagnosis** (type and year): Mixed dementia (Alzheimer’s and Frontotemporal dementia), 2017

**Joined the group:** 2018

**A bit about me:** I was born in a small village called Merksplas in Belgium. My father was a dairy farmer but I chose to study digital technology and worked for 30 years as a telecom software engineer, spending a long time in Norway, Germany, Israel and China for my job. I worked with people from all over the world.

My priorities are: to give a voice to others who aren’t heard; to help support other countries to develop their own groups; to assist with vital research; and to promote rights and better services for all, while I can. I really enjoy working with and assisting researchers, on all the various projects they are working on, for us. It’s nice to be part of something that is actually making changes, and being like a family in the group.

How can any country or organisation really produce what people affected by dementia need, without speaking to and hearing from those with the lived experience, the very people who are experts by their own experience? This is why working groups are important. These collaborations will then support, promote and produce better services, research, and care. They will also help us and our families to live better lives.

**Chris Roberts, Chairperson**

I joined the Working Group back in 2016, after first hearing about its formation at a dementia conference in Scotland. I thought it was a great platform and group to bring our countries together, for collaboration and to give an international voice to those affected by dementia. I joined as Vice-Chairperson for two terms and now as Chairperson.

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**Kevin Quaid, Vice-Chairperson**

I joined the EWGPWD because it gives me a chance to represent my country on a European stage and to give a voice to people with dementia, but especially to give people with LBD a voice, because I still think that the scale of people who actually have LBD is so underestimated and I want to change that.

My priorities are quite simple: I want the rights of people listened to and understood; and to make sure nothing happens or no decision is made about us unless we are included in both the question and the answer. More needs to be done to find a cure for dementia, and more needs to be done to ensure that people who have dementia are given a proper diagnosis. The stigma needs to be, once and for all, completely taken out of the equation when talking about dementia.

Working groups are of vital importance in each and every country and it is of even more importance that we have our European working group, to look at how different countries deal with dementia and the different advancements that each country makes. These can then be shared. One glaring example is how some countries can offer DaTscan and other countries don’t. This is a brain scan which can identify whether a person has LBD or not.

**Bernd Heise, Vice-Chairperson**

There are many reasons for my commitment to people with dementia: I first encountered dementia about 20 years ago, in the company where I worked. I met an employee who had significant memory problems. He had to leave the company within a few weeks. Before that experience, I didn’t even know that dementia could affect younger people also. Now, I have dementia myself in the early stages and would like to stand up for people who are in a similar situation to me.

Before I joined the EWGPWD, I learned a lot about dementia at the Alzheimer’s association in Munich and I later became a member of the advisory group of the Deutsche Alzheimer Gesellschaft (German Alzheimer’s association). There, I was asked whether I would like to support the EWGPWD, which I gladly accepted.

I see my task in the EWGPWD as giving people with dementia a voice, and ensuring that various areas of help and support are developed. There is an urgent need to educate people about the problems and concerns of people with dementia.

I hope to be able to pass on my knowledge and experience regarding Alzheimer’s, in the group and beyond. I also see a specific task for myself: to push technical supports for people with dementia, because of my professional background and my great interest in this topic. My goal is that these technical supports will enable people with dementia to live independently, for longer. The University of Munich and the Munich Alzheimer’s association have started a project to create technical systems for people with dementia, based on an assistive voice computer.

As a person who has always been in contact with other people and has stood up for others, I am convinced that exchanging ideas with one another and thinking outside our borders is very, very important in order to develop new ideas. I see a chance to do just that, in the EWGPWD. We have the opportunity to bring together national strategies for people with dementia, to listen to and learn from each other. In the EWGPWD, I see the chance to actively do something for people across Europe who have dementia.
EPAD: Global efforts and cooperation to advance research in Alzheimer’s disease and prevent dementia

As the European Prevention of Alzheimer’s Dementia (EPAD) project draws to a close, Alzheimer Europe looks back at the innovative project and speaks to its co-leads, Craig Ritchie and Serge Van der Geyten, about their reflections on the project.

There is now compelling evidence that Alzheimer’s disease takes hold in the brain decades before dementia symptoms appear, providing a window of opportunity for preventative intervention. As a result, today’s research increasingly focuses on this pre-symptomatic phase, with the aim of delaying or preventing dementia.

An innovative project

The European Prevention of Alzheimer’s Dementia (EPAD) consortium is an interdisciplinary research programme spanning public and private sector organisations across Europe. EPAD was funded by the Innovative Medicines Initiative (IMI) in conjunction with 39 partner organisations for a period of 5.5 years, until 30 October 2020, aiming to improve the understanding of the early stages of Alzheimer’s disease and deliver new preventative treatments.

While one objective was to undertake a multi-arm Phase II adaptive clinical trial for the secondary prevention of Alzheimer’s dementia, many other values and assets arose during the course of the project. The disease modelling work performed by the team will improve the understanding of the Alzheimer’s disease process over time, identifying important biomarkers which can be used to inform management of patients and new targets for drug development and help improve recruitment/selection into clinical trials for Alzheimer’s disease in Europe and worldwide.

EPAD has also created a platform trial structure that allows multiple arms to enter a single trial platform located in the EU to allow more efficient development. Although the Proof of Concept (PoC) platform was set-up and a process for initiating each appendix was developed, the PoC trial was not initiated. This platform will remain accessible. The EPAD work and the input of each EPAD work package throughout the project has resulted in significant outcomes and contributions to the scientific community.

The EPAD Longitudinal Cohort Study

EPAD has created the first single, pan-European register of over half a million people across the risk spectrum for dementia. From this register, research participants were invited to join an EPAD cohort of at-risk subjects: the EPAD Longitudinal Cohort Study (LCS).

A key achievement of the EPAD project was the establishment of the LCS that has...
screened over 2,000 participants across 30 European study centres and collected a wide range of cognitive, clinical, neuroimaging and biomarker data to help further our understanding of the early stages of Alzheimer’s disease. Screening into the LCS was stopped on 29 February 2020 and a total of 2,096 participants had been screened. Although the LCS is no longer following up participants, it provides an ongoing legacy through open access to data and a vast range of possibilities for sample access.

**Open-access data sets**

The EPAD LCS Research Access Process (ERAP) was set up and designed to give academic researchers, institutions and companies from all over the world a simple and quick way to access the data collected during the LCS. Four versions of the LCS database have been released and the last one includes all complete data up to the date the study was closed. Moreover, a very large Bioresource is available for sample access. The EPAD Bioresource consists of over 100,000 samples consisting of blood, CSF, saliva and urine that were collected annually from research participants throughout their participation in the LCS.

The current EPAD database, provided by Aridhia, is open-access, ensuring the use of the data to the Alzheimer’s disease research community worldwide. Data access is free to all researchers. Further details on the available data and samples for researchers and the process for accessing them can be found on the EPAD website. The EPAD consortium is pleased that even with the LCS finished, it continues to be an important resource which generates new data for research.

**The way forward**

The Alzheimer’s Disease Data Initiative (ADDI) aims to move Alzheimer’s disease innovation further and faster by connecting researchers with the data they need to generate insights to inform development of new, better treatments and diagnostic tools for Alzheimer’s disease and related dementias. ADDI has recently launched its Alzheimer’s disease Workbench, a cloud-based platform for scientists to accelerate discoveries and innovations for Alzheimer’s disease and related dementias. ADDI is supporting the EPAD project and EPAD datasets will be findable via its workbench to provide even greater value to the global neuroscience research community. Bringing the EPAD data and the EPAD researcher community together through ADDI will ensure the longevity and the value of the EPAD project.

**A few words from the project leaders**

Alzheimer Europe, a partner in the EPAD project, asked representatives of the two organisations co-leading the project, Craig Ritchie (University of Edinburgh) and Serge Van der Geyten (Janssen Pharmaceutica NV) to share their thoughts regarding various aspects of the project. They worked together to send joint answers to our questions.

**EPAD aimed to improve the understanding of the early stages of Alzheimer’s disease and streamline the testing and development of preventative treatments. How well do you think these key aims were met?**

EPAD aimed first to recruit and deeply phenotype potential clinical trial participants across Europe. This was clearly achieved by the establishment of the Longitudinal Cohort Study and by collecting what is an incredible dataset, open access and publicly available to the research community. This dataset is going to be continually enriched with genomic, proteomic and imaging data among others. There is an incredible excitement about what is going to come out of the high quality and large dataset that we developed through the EPAD Longitudinal Cohort Study. EPAD secured some funds to maintain this dataset and make sure that we could continue to allow free access to it.

Secondly, EPAD planned to study new drugs in a well-designed Phase II proof of concept trial. The EPAD platform was developed to speed up the development of effective, safe medicines which slow or prevent the development of Alzheimer’s dementia. It is a pity we never had a drug to be able to start the EPAD proof of concept study. However, pharmaceutical companies have learned a lot from stepping into this collaboration. We still think that a platform trial such as the one we tried to set up is the future if we want to accelerate drug development.

**Can you share some of the insights that may have emerged during the project?**

One thing that really characterises EPAD is the incredibly large consortium that was well funded with lots of partners and members within each of those partnerships contributing and believing in what we were doing.

Another insight that we regained is still ongoing. Some projects globally are still looking at platform trials and we may be asked to come back in and share our experience, so that the field will still benefit massively. Although, we never got a drug across the line, the knowledge and learnings we gained about what to do and what not to do are incredibly important to inform the next steps and there will be a next stage.
What were the main obstacles encountered in this global work?

EPAD was an interdisciplinary research initiative combining expertise from 39 European organisations. Although EPAD was an EU funded research project, Alzheimer’s research is a global endeavour that needs to be globally addressed, not just at a European level. The field, in terms of new drugs available for patients, hasn’t moved much further since we started the project several years ago. The main lesson there and going forward is that the EPAD proof of concept study was maybe a bit too ambitious in the beginning. However, we are confident that a platform like this will be set up again in the not too distant future and we believe that pharmaceutical companies will support it. One crucial factor for the success of such a future platform will be the availability of regulatory accepted intermediate phenotypes, as having to rely solely on a cognitive endpoint for trial success leads to too long and too costly clinical trials.

Some obstacles weren’t necessarily scientific or operational, they were more to do with working within a particular framework. With all the energy and the ideas we had, we were disappointed when the legal structures and governance around us were not as flexible and as innovative as we were. It is something, however, which began moving forward but timelines eventually worked against us. If people are going to embark on projects of this scale, they need to make sure that all stakeholders are fully on board and are willing to make adaptations to their way of working.

How do you think the outcomes of the EPAD project can contribute to the future of Alzheimer’s disease research?

The most obvious one is the incredibly rich data source compiling both data and samples that have been collected annually from research participants throughout their participation in the Longitudinal Cohort Study. EPAD has made this database open access and that is going to serve the scientific community for years to come. We set up the benchmark for how we allow data to be accessed in the future, that will be of huge value going forward.

We already saw explicit references to the EPAD project on how we did our work and how to make use of the data generated. The EPAD set up has been and is being used as a template by other projects looking at establishing a trial platform framework, which is quite amazing. We started the project with a relatively small group of enthusiasts and ended up with over 400 people working on the project including senior academics, senior company executives as well as a very wide range of early career researchers. With the collaboration of a very diverse group of experts, we built something strong and we imagine that all contributors enjoyed the way we worked together as much as we did. We want to work like that in the future with this incredibly open collaboration.

Finally, could you share one or two personal highlights from the past years?

The main highlight was having the incredible privilege of being part of such a wonderful community that really cares about people with Alzheimer’s disease and has devoted much of their lives to finding a treatment for this terrible disease. Moreover, it was a great experience to interact, collaborate and spend time with our research participants. In EPAD, research participants were at the heart of the project. We were committed to involving them as much as possible in the development of the project, empowering everyone to play an active role in our progress.

Acknowledgement

The EPAD project has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union’s Seventh Framework Programme (FP7/2007–2013) and EFPIA companies’ in kind contribution.
PARADIGM: Making patient engagement in the development of medicines a reality

Patients ought to be more involved in the process of developing medicines. Putting this seemingly simple principle into practice, however, is far from easy. The goal of the IMI-funded PARADIGM project (2018–2020) was to develop a framework which could enable effective, meaningful and sustainable patient engagement.

With this in mind, PARADIGM aimed to develop a framework which could enable effective, meaningful and sustainable patient engagement (PE) in the development of medicines and demonstrate the “return on engagement” for all stakeholders.

The project received funding from the IMI and was co-led by the European Patients’ Forum (EPF) and the European Federation of Pharmaceutical Industries and Associations (EFPIA). It involved 34 partners representing the different stakeholders typically involved in medicines development (e.g. patient organisations, pharmaceutical companies, academia, HTA bodies and regulators, etc.). Five patient organisations with different experiences in patient involvement took part in the project: European Patients’ Forum, European AIDS Treatment Group, Rare Diseases Europe, Sant Joan de Déu Research Foundation and Alzheimer Europe. Sant Joan de Déu Research Foundation and Alzheimer Europe brought to the project the perspective of young patients and of people living with dementia, respectively. This helped to raise awareness of the value of involving people with dementia and young patients in patient engagement activities and helped to ensure that their specific needs are taken into account, as well as the support that should be in place to enable their involvement.

Within the whole process of developing medicines, the project particularly focused on three points of this process:

- research and priority setting
- design of clinical trials
- early dialogues with regulators and HTA bodies.

Main outcomes of the project

The project was designed sequentially, with each step informing and guiding the next one. The main activities and outcomes of the project included:

Online survey

The survey aimed to identify the needs and expectations, of the different stakeholders, for
involving patients in the process of developing medicines. The survey was completed by 372 respondents from 48 countries.

- Overall, participants in the survey had the impression that, currently, the involvement of patients in medicines development was lacking, and the ideal expectation was that it should be much more widespread, particularly in the design of clinical trials.

- The more important challenges identified by the participants in the survey from the patient community included: (i) clear and open communication and (ii) shared goals between the different stakeholders involved. On the other hand, the most important resources needed were those used to measure the impact of patient engagement activities and those used to identify and evaluate where their contribution would be most valuable.

### Two face-to-face consultations

One of these consultations was organised by Alzheimer Europe and involved all members of the European Working Group of People with Dementia (EWGPWD). Important messages from people affected by dementia included:

- People with dementia are “experts by experience” and their input is unique.

Some of the suggested ways to involve people with dementia in a meaningful way, were:

- existing stigma and misconceptions surrounding dementia should be addressed
- people with dementia and carers should receive relevant and accessible information and appropriate support
- reasonable adjustments should be made to address their needs
- relationships should be based on mutual respect
- education about dementia (beyond medical aspects) should be provided to the stakeholders interacting with them.

### Set of criteria

A set of criteria for assessing effective and meaningful patient engagement practices. A Delphi technique was used to develop the set of criteria. It included two online surveys and face-to-face workshops involving different stakeholders. A few members of the EWGPWD were involved in this work. The table at the top of this page summarises the results.

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**Table: Set of Criteria for Assessing Effective and Meaningful Patient Engagement Practices**

<table>
<thead>
<tr>
<th>Criterion</th>
<th>Weight</th>
<th>Description</th>
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</thead>
<tbody>
<tr>
<td>Overall</td>
<td></td>
<td></td>
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<tr>
<td>Aim and Objectives</td>
<td>A1</td>
<td>Aim and Objectives</td>
</tr>
<tr>
<td>Target Patients Involved</td>
<td>A2</td>
<td>Target Patients Involved</td>
</tr>
<tr>
<td>Involvement and Participation</td>
<td>A2</td>
<td>Involvement and Participation</td>
</tr>
<tr>
<td>Legal and Ethical Consideration</td>
<td>A2</td>
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<tr>
<td>Code of Conduct</td>
<td>A2</td>
<td>Code of Conduct</td>
</tr>
<tr>
<td>Capacity Building</td>
<td>A2</td>
<td>Capacity Building</td>
</tr>
<tr>
<td>Resources</td>
<td>A3</td>
<td>Resources</td>
</tr>
<tr>
<td>Patient Engagement Impact</td>
<td>A3</td>
<td>Patient Engagement Impact</td>
</tr>
<tr>
<td>Evaluation of the PE Practice in the Design of Clinical Trials</td>
<td>A3</td>
<td>Evaluation of the PE Practice in the Design of Clinical Trials</td>
</tr>
<tr>
<td>Sustainability</td>
<td>A3</td>
<td>Sustainability</td>
</tr>
</tbody>
</table>

*Weight: Criteria were ranked (from highest to lowest priority) according to the average score each criterion received from the experts of the Delphi panel.*
of the Delphi process and specifies the criteria which should be considered for each of the three decision-making points (i.e. setting research priorities, designing clinical trials and early dialogues).

**Gap analysis**

A gap analysis which resulted from comparing the PARADIGM set of criteria against current practices. Two overall gaps and sixteen criteria-related gaps were identified. Of those, the following gaps were prioritised and selected to be addressed by PARADIGM:

- reporting and dissemination of patient engagement activities in the public domain
- identification and selection of people to involve in the patient engagement activities
- legal agreements to be used in patient engagement activities written in a clear and accessible way
- management of potential conflicts of interest, disclosure, transparency and accountability
- monitoring and evaluation of the impact of the patient engagement activity
- formation and maintenance of long-term partnerships.

**PARADIGM Patient Engagement Toolbox**

The Toolbox includes tools for planning, conducting, reporting and evaluating patient engagement in medicines development. The next edition of the Dementia in Europe magazine (June 2021) will include an article about the Toolbox.

**Patient Engagement Open Forum (PEOF)**

Organised annually in Brussels, with the exception of the 2020 PEOF which, due to the COVID-19 pandemic, was organised online as a series of events from June to November 2020. Recordings of all sessions are available, here: [https://patientengagementopenforum.org](https://patientengagementopenforum.org)

Further information about the survey, consultations, Delphi and gap analysis will be published in two articles by Faulkner and colleagues, which have been submitted for publication in the Journal Health Expectations and in the Journal of Therapeutic Innovation and Regulatory Science.

### The contribution of the European Working Group of People with Dementia

<table>
<thead>
<tr>
<th>Activities</th>
<th>Contribution of EWGPWD</th>
<th>When</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs and expectations for PE in medicines development</td>
<td>Participation in survey and face-to-face consultation with all members of EWGPWD and supporters</td>
<td>2018</td>
</tr>
<tr>
<td>Set of criteria for assessing PE practices (Delphi)</td>
<td>Two members of the EWGPWD and supporters (2018–2019) involved in the process (online surveys and workshop)</td>
<td>2018–2019</td>
</tr>
<tr>
<td>Development of tools and toolbox</td>
<td>Participation in face-to-face and online workshops (one member of the EWGPWD and supporter) and several mini-consultations with all members of the EWGPWD</td>
<td>2019–2020</td>
</tr>
<tr>
<td>Development of PE Monitoring and Evaluation Framework</td>
<td>Consultation with all members of EWGPWD</td>
<td>2019</td>
</tr>
<tr>
<td>Communication and dissemination</td>
<td>Blogs on PARADIGM website and articles in Alzheimer Europe newsletter and Dementia in Europe magazine</td>
<td>2018–2020</td>
</tr>
</tbody>
</table>

### A few words from the project leaders

Alzheimer Europe, a partner in the PARADIGM project, asked representatives of the two organisations co-leading the project, Magda Chlebus from the European Federation of Pharmaceutical Industries and Associations (EFPIA) and Nicola Bedlington from the European Patients’ Forum (EPF), to share their thoughts regarding various aspects of the project. They worked together to send joint answers to our questions.

**Q: PARADIGM aimed to provide a unique framework to enable structured, effective, meaningful, ethical, innovative, and sustainable patient engagement, as well as to demonstrate the “return on engagement” for all players. How well do you think these key aims were met?**

Another way of summing up these aims is that PARADIGM aimed to make patient engagement in medicines development easier for all. This was clearly achieved by the creation of the tools, recommendations and resources that are now centralised in the Patient Engagement Toolbox. The materials cover the planning, implementation and reporting phases of patient engagement activities.

The tools that were developed did not come from an “assumed need”; rather, they are the results of a robust gap-analysis conducted in the first phase of the project. Importantly, we also identified gaps that the consortium decided not to address, because these were being taken forward by sister initiatives. An example of this is the work of the National...
Health Council on calculating Fair Market Value for the involvement of patients and their representatives in medicines development.

When it comes to the “return on engagement”, it is clear that capturing this is complex, given the many factors that influence the impact of meaningful patient engagement. The Patient Engagement Monitoring and Evaluation Framework with metrics, was created to help partnerships between patients and/or patient organisations, bio-pharmaceutical companies, regulators and health technology assessment (HTA) bodies to self-evaluate the progress and impact of patient engagement in the medicines development lifecycle, for all stakeholders involved. The objective of this tool is to support learning to enhance meaningful patient engagement; to help users to understand the pathway towards real, tangible impact and benefits of patient engagement; and to demonstrate better decision-making in medicines development. Now, the next challenge for the community is to use it! We are calling for stakeholders to work with it internally and, moreover, to share the aggregate results to further build the case for patient engagement.

Q: Can you share some of the insights that may have emerged during the project, regarding both the importance of, and the existing barriers to, “good” patient engagement?

Three words: culture, culture and culture. When a common culture and understanding of the importance of patient engagement for all stakeholders exists, together with trust amongst partners, there are no more barriers to meaningful engagement. This is true in all lines of work, and especially when stakeholders with different cultures and backgrounds need to work together. In PARADIGM, we immediately put trust at the centre, to co-create tools and recommendations which responded to real needs out there and which are fit for purpose. It is only by developing a common culture of engagement between all the stakeholders that the field will thrive. Of course, the rationale and the approach may differ, but when the objective is common, and commonly understood, there are no longer any intellectual or practical barriers.

Q: Is any of the work of the project planned to continue? If so, what form will this take?

There was never a plan to continue the project per se, as we delivered what we promised. What is important now, in order to have a real impact, is that the resources are used and refined according to the specific needs of the different stakeholders, phases of development and geographic locations. We made a huge step in sustainability, by ensuring that the Toolbox will be available for the next three to five years via both the Patient Focused Medicines Development’s SYNaPSe and EUPATI Foundation’s Toolbox. These are initiatives that we would like to thank for the very productive working relationships we developed in delivering three Patient Engagement Open Forums (PEOF) in the framework of PARADIGM. Efforts are now focused on keeping this structure alive, with EPF replacing PARADIGM, to organise a PEOF in 2021, without the funding of the IMI. We would like to thank the funders that have already contributed to help make this happen. It is an enormous collective effort that makes sense, because this year, we had about 1,500 registered participants for an event about patient engagement in medicines development. We are proud to have triggered this!

Of course, PARADIGM would have achieved very little without the ongoing dedication, hard work, creativity and expertise of our Consortium members, and we would like to thank Alzheimer Europe, in particular, for the unique and invaluable perspective that they brought to the table. We hope our collective work will be of real value to patient communities across Europe.

Acknowledgement

The PARADIGM project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 777450.
Neuronet programme launches Knowledge Base

The Neuronet coordination and support initiative has launched a new Knowledge Base dashboard, containing key information on 18 neurodegeneration research projects encompassing EUR 386 million of funding.

The members of the Neuronet programme are pleased to announce the launch of a pan-European Knowledge Base which brings together key information about the 18 projects of the Innovative Medicines Initiative (IMI) neurodegeneration portfolio.

Neuronet is a three-year coordination and support action that began in March 2019. It consists of a small number of active partners in a variety of IMI neurodegeneration projects and related initiatives. Its partners are specialists in complex/project management, data sharing & re-use, drug development, patient engagement, communication, sustainability and regulatory/Health Technology Assessment interactions.

The Knowledge Base is a comprehensive resource and an integral part of Neuronet’s endeavour to boost collaboration across the research portfolio by assisting in identifying gaps, multiplying the portfolio’s impact and enhancing its visibility with related initiatives in Europe and worldwide.

Programme overview

As well as providing a summary overview of the IMI neurodegeneration research programme through its interactive dashboard, the Neuronet Knowledge Base already includes links to over 380 scientific publications and more than 350 deliverable reports, acting as a one-stop shop for anyone interested in exploring the diverse projects and outputs of the programme. All of these are updated on a regular basis, providing users with direct access to the scientific knowledge stemming out of these public-private research collaborations.

Knowledge Base tools

An “Asset Map” gives a comprehensive view of the different assets resulting from the projects, such as genetic datasets, clinical cohorts, and data platforms. The interactive map allows users to obtain more detailed information about the specific assets of each project. Furthermore, the Knowledge Base offers access to a regulatory, health technology assessment & payer engagement Decision Tool to help researchers identify the key processes and procedures for engagement with these stakeholders at key points in the development of an asset.

Staying up-to-date on scientific progress and activities

In addition to project and programme-related information, users can also access an agenda listing key upcoming scientific conferences and view a feed with the latest project-related activities.

The Knowledge Base can be accessed here: https://kb.imi-neuronet.org/

Acknowledgement

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.
Empowerment is important for people with dementia in order to remain engaged with significant others, and to remain involved in society and the decision-making process regarding their care and support. SPAN+ is a Dutch project aiming to develop effective empowerment interventions, which are applicable for people with dementia at home as well as in care homes. Charlotte van Corven, a PhD student working on the SPAN+ study, tells us more.

The concept of empowerment seems promising for people with dementia for living their lives as they want to. It may contribute to the shift from task-oriented care, which has a focus on the illness, to person-centred care and relationship-centred care – approaches that focus on the whole person and the care relationship. An empowering approach may encourage the person living with dementia to focus on talents and capabilities, and may contribute to reciprocity in relationships. It helps to focus on what is possible, instead of what is no longer possible.

The World Health Organization defines empowerment as a process through which people gain greater control over decisions and actions affecting their health. However, definitions may differ depending on the population in which the concept is applied. Considering that dementia causes cognitive impairment and behavioural changes that can affect a person’s control over their own decisions and actions, the concept of empowerment may differ between people living with dementia and people living without dementia.

In our SPAN+ study, we aim to explore what empowerment means and includes, specifically for people living with dementia, and to develop interventions that support people living with dementia and their carers in this empowerment process, thus providing concrete opportunities for healthcare professionals and informal carers to address and support strengths.

The SPAN+ project is executed by a multidisciplinary research team from the University Medical Centre in Nijmegen (Netherlands), consisting of Charlotte van Corven (human movement scientist), Dr Annemiek Bielderman (human movement scientist), Prof. Dr Debby Gerritsen (psychologist), Prof. Dr Maud Graff (occupational therapist), Dr Ruslan Leontjevas (psychologist, methodologist) and Dr Peter Lucassen (general practitioner). Moreover, people living with dementia and their representatives are involved in all phases of the project.

Collaboration with Alzheimer Europe

The SPAN+ team works in close collaboration with Alzheimer Europe. At the start of the project, we jointly performed a survey to identify existing empowerment interventions in Europe, using Alzheimer Europe’s large network of national associations.

Furthermore, the European Working Group of People with Dementia (EWGPWD) was
consulted on the design of the study; on the results of our qualitative study on defining empowerment for people living with dementia; and on the concept version of the SPAN+ empowerment interventions. The latter two subjects were also discussed with representatives of Alzheimer associations during one of the Alzheimer's Association Academy meetings. In this way, we can be sure that the course of the project reflects the priorities and views of all stakeholders, and that results will be applicable across Europe.

**Results and implications of the European survey**

With the European survey, we aimed to identify effective and usable elements of empowerment interventions throughout Europe. 72 people from 23 European countries filled in the survey. Their responses mentioned a total of 97 interventions that they considered to be empowering. We concluded that empowering interventions can have a broad range, focusing on different levels. Interventions ranged from nutritional guidance at the individual level, to dementia-friendly societies at the societal level. Effective interventions that were specifically aimed at empowering people living with dementia, however, appeared to be scarce.

To explore what empowerment means and includes, for people living with dementia, we performed a qualitative study with focus group discussions and individual interviews with people living with dementia, their family carers, and healthcare professionals. Four themes were identified as important aspects of empowerment: Having a sense of personal identity; Having a sense of choice and control; Having a sense of usefulness and being needed; Retaining a sense of worth. Based on these themes, a conceptual framework of empowerment for people with dementia was developed (see image on page 20).

The four themes seem to be important both at home and in nursing homes, and at different stages of dementia. To illustrate, choices made by a person living with early dementia residing at home will be different from choices of a person living with advanced dementia residing in a nursing home. Even though the specific choices may differ, they may lead to the same feelings of self-determination and control. Practical detailing of support, therefore, differs.

More information on these results can be found in our recently-published scientific article in the International Journal of Nursing Studies.

Based on these four themes of empowerment, we developed two empowerment interventions for people living with dementia at home and in a nursing home, respectively. These interventions aim to reflect and act on wishes and needs of people living with dementia and their family carers regarding the four themes of empowerment.

**Step 1.** The person living with dementia and their family carer discuss questions about the four themes of empowerment, using specially-developed SPAN+ conversation cards. They write their answers on the back of the cards.

**Step 2.** During one or more visits, the healthcare professional explores the answers on the cards.

**Step 3.** Together, the person living with dementia, their family carer and the healthcare professional formulate objectives for each of the four themes.

**Step 4.** They all work together to put these objectives into practice.

For people with dementia living in a nursing home, an adapted version of the conversation cards are used by health care professionals to reflect on the four themes of empowerment for their residents.

Again, objectives are formulated for each of the four themes of empowerment, together with the person living with dementia and their family carer. Furthermore, healthcare professionals work on their personal professional development regarding empowerment: they observe a colleague, give specific attention to empowerment themes during their work, and jointly reflect on this. A multidisciplinary project group within the health care organisation adjusts the SPAN+ intervention to fit the local setting.

**Involvement of people with dementia, carers and healthcare professionals**

In addition to the important role played by the EWGPWD and Alzheimer Europe, people living with dementia and their representatives are involved in all phases of the project, to ensure that the design, data collection and implementation of the results are suitable for all stakeholders.

Firstly, people living with dementia, their family carers and healthcare professionals participated in our qualitative study, in which we investigated needs and wishes for an empowerment intervention.

Furthermore, an advisory expert team – which consists of a nursing assistant, a dementia case manager and a quality assurance officer for participating long-term care organisations in the Netherlands – is assisting us throughout the entire project.

**What comes next?**

An important step in advancing the knowledge on empowerment is to review existing literature, and to place our framework of empowerment in the broader perspective of said literature. This will allow us to gain further insight into the process of empowerment. We will also test the feasibility and effectiveness of the two SPAN+ empowerment interventions.
As Norway publishes its Dementia Plan 2025, can you outline the key areas of focus for the Plan?

The goal of the Dementia Plan 2025 is to build a more dementia-friendly society, where people with dementia are cared for and integrated in the community. The Dementia Plan 2025 includes four main priority areas:

1. co-determination and involvement
2. prevention and public health
3. good and cohesive health and care services
4. planning, competency and knowledge development.

It is well known that when the elderly population increases, more people will develop dementia. It is estimated that at least 100,000 Norwegians currently have a dementia disease and a sharp rise in cases is expected in the coming years. This has an impact on the demand for health and care services and we must find sustainable solutions for the future. Dementia is a significant public health problem and there is a need for greater focus on the prevention of dementia.

The main challenge outlined by the Norwegian Directorate of Health is that there are still too many people with symptoms of cognitive impairment who are not being assessed and diagnosed. To illustrate, the register data shows that only 45,000 people were registered with a dementia diagnosis in 2018. This is a low figure, considering that the number of people with dementia in Norway in 2020 is an estimated 102,000. A timely diagnosis and post-diagnostic follow-up were one of the main priorities of the Dementia Plan 2020, however, continued focus on this issue will be necessary. This involves encouraging people with possible symptoms of dementia to seek help and helping healthcare personnel to become more skilled at identifying signs of cognitive impairment.

Another frequent comment we received during our work on the new dementia plan, is the lack of activities, both for those living at home and for residents of nursing homes. In the Dementia Plan 2025, we will continue to focus on activity initiatives. It is important to ensure that the content of services is experienced as both attractive and meaningful. It is also important for the services to function as respite for family members.

The Dementia Plan 2025 will focus on these and several other areas.

What lessons have been learned from the previous Dementia Plan 2015 and Dementia Plan 2020?

We have good experiences with national dementia plans. A stand-alone dementia plan contributes to raise awareness of dementia. It recognises the value of people with dementia and their families in society. It is also a platform for policy change and provides the basis for action.

This is the third dementia plan in Norway and our new plan is based on the results and experiences from our last two plans. There has been a positive development since the Dementia Plan and through the Dementia Plan 2020, there has been an increase in the number of municipalities that have interdisciplinary teams with competency in dementia, national professional guidelines for dementia were published in 2017 and from 1 January 2020, the government introduced a requirement for municipalities to offer adapted day activities for people with dementia. Even though there has been a positive development, many challenges remain and there is still a need for national action.
We are continuing many of the measures from the Dementia Plan 2020, in addition we have new measures and the scope of the plan has been expanded. The Dementia Plan 2015 and the Dementia Plan 2020 were limited to municipal health and care services. There is still a need to develop good and flexible municipal health and care services. However, it is also necessary to include specialist health services and other sectors in society. Dementia Plan 2025 therefore also includes the specialist health service.

How were people with dementia, their families and carers involved in the development of the new Plan?

The Dementia Plan 2025 has been developed in cooperation with people with dementia and their families and carers. We have held dialogue meetings and participated in meetings organised by the National Association of Public Health. Through the National Association of Public Health, we have had meetings with peers, people with dementia and relatives. As an interest organisation for people with dementia and their families, the Norwegian Health Association has a unique experience base.

Is there an allocated budget to implement the actions/commitments within the new Plan?

The municipalities and the regional health authorities are responsible for organising their health and care services, including services for people with dementia. This means that services will generally be financed through block grants for the municipal sector and basic allocations to regional health authorities.

In addition to the general financing of the services, there will be allocated annually NOK 45 million to follow up the plan and the research efforts from the Dementia Plan 2020 are continued. New initiatives may be added during this period.

What do you believe is the key to the successful implementation?

The share of older persons, particularly those aged 80 and over, is expected to increase significantly in the years ahead, and the incidence of dementia increases with age, and it is estimated that the number of people with dementia will double by 2040. These challenges place great demands on the management, planning, organisation and administration of services in the years ahead.

A key element is to ensure long-term planning in the municipalities and regional health authorities. We hope that the strategies and measures of the Dementia Plan 2025 will help to put dementia challenges on the agenda for municipalities and regional health authorities, and that people with dementia and their families and carers are involved in planning processes.

Secretary General of Nasjonalforeningen for folkehelsen, Mina Gerhardsen, reacts to the publication of the Norwegian Dementia Plan 2025

What is the reaction of Nasjonalforeningen for folkehelsen to the newly published Dementia Plan 2025?

We welcome the plan and have worked intensely for the realisation of a third Plan, as many of the objectives in the previous plans had not yet been achieved. We also appreciate the good work that has been done in the process of writing the Plan, where the Ministry has had many meetings with people with dementia and their carers. Their voices resound throughout the document.

It is a good plan, but it also lacks resources and financial back-up to implement the commitments it contains. This is especially clear as new research showing dementia prevalence in Norway is 25% higher than previously presumed.

Are there any measures you are particularly pleased to see included?

We are pleased with the fact that this Plan, unlike the two which preceded it, includes the national specialist health care service,
as part of the health services that should be optimised for people with dementia, as well as social inequality and a public health perspective on prevention and the inclusion of research as a key tool for combatting dementia.

Does Nasjonalforeningen for folkehelsen have a role in the governance or oversight of the Plan?

As a Non-Governmental Organisation (NGO) in Norway, we do not have a natural role in overseeing public services, but we will continue to voice issues on behalf of people with dementia and their carers. We do have a role in implementation of some of the programmes described in the Plan, but sadly we have yet to receive public funding for this work.

Following the publication of the Plan, what are policy priorities for Nasjonalforeningen for folkehelsen?

Faced with the high and rapidly raising numbers in dementia prevalence, our main goal is to campaign for a large raise in public and private funding of dementia research. At the same time, we realise that finding an effective treatment or cure can take long time; better dementia care and a dementia friendly society are needed for those living with dementia today. In order to achieve this, Norwegian municipalities need more resources, we need to educate more health workers and we need to develop more and better care technology.

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Minister for Solidarity and Health outlines the future of dementia policy in France

Alzheimer Europe interviewed the French Minister for Solidarity and Health, Olivier Véran, about the future of dementia policy in France following the conclusion of the country’s Neurodegenerative Disease Strategy in 2019. We also spoke to Joël Jaouen, President of France Alzheimer, for his thoughts on the future priorities for dementia policy.

France’s Neurodegenerative Diseases Plan came to a conclusion at the end of 2019 – what are your reflections on this programme?

The choice to bring together three neurodegenerative diseases (Alzheimer’s, Parkinson’s and Multiple Sclerosis) in a single plan was not immediately understood. Five years later, we have assessed the plan positively overall. Of course, a 30-year-old with Multiple Sclerosis does not have the same needs as an older person with Alzheimer’s disease. But the approach proved effective in several ways. Other diseases have benefitted from the achievements of the three successive Alzheimer’s plans since 2000. For example, respite platforms are now open to all neurodegenerative diseases.

This aside, we also addressed the specificities of each disease. Encouraging an earlier diagnosis for Alzheimer was one of our priorities. The translational approach has proved to be successful in developing and coordinating research on neurodegenerative diseases. Seven regional teaching and research centres of excellence have joined the European centres of excellence as part of the COEN (international network of centres of excellence in neurodegeneration).

The Plan was evaluated by two external academics – can you give us an insight into the conclusions they have reached?

They have made seven recommendations, the main one being to extend the plan in the form of a roadmap created with patients’ associations, with a basis in the Global Action Plan on Dementia developed by the World Health Organization (WHO). The academics also stressed the need for alignment with other strategies, such as the national health strategy’s “priority for prevention” or the national policy for the elderly.

Is there likely to be another national plan which focuses on dementia or neurodegenerative diseases?

We have chosen to continue the plan for two years as a roadmap focused on a few priorities with patient associations. I’m convinced it’s important to include people living with the condition, looking for their input and experiences.

“Some questions have insufficiently been addressed so far: dementia is clearly a question that affects older people, but we must adapt the answers to the needs of young people with dementia.”

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Our aim is to consolidate some achievements such as the diagnosis strategy which now needs to be adopted by GPs. We also need to evaluate some pilots before deciding what comes after. Many projects have been funded during the plan, prioritising territorial initiatives, which should now be evaluated to identify the most efficient practices. This is also why we need this transition.

Some questions have insufficiently been addressed so far: dementia is clearly a question that affects older people, but we must adapt the answers to the needs of young people with dementia. That was a weakness of the former plan and we will try to make some progress in the next two years.

Much remains to be done, but nowadays, the challenges are quite different. If I focus on the diagnosis, one of our priorities, the context is very different. In France, 28 resource and research memory centres for complex and atypical cases, as well as 500 to 600 memory consultation centres provide diagnostic
services for people suspected of having dementia. This is considered as being sufficient. We now have to convince professionals and families of the usefulness of the diagnosis despite the absence of curative treatment. France has proposed a strategy for diagnosis which is part of the European Joint Actions on Dementia. The priority is now to implement this strategy: this means a training effort, particularly for general practitioners.

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Despite evidence showing that the pathological process of Alzheimer’s diseases starts many years before clinical symptoms appear, as well as evidence about the value of early detection, the diagnostic rates remain too low. General practitioners have a key role. We will soon launch, with the dedicated national agency, the ANDPC (Agence Nationale pour le Développement Professionnel Continu), a national training programme to address all brakes from ethical matters to technical questions such as knowledge of different diagnosis tests.

What other work is the French Government currently undertaking in relation to dementia?

A number of our strategies benefit people living with dementia such as the caregivers strategy, the mental health strategy and the national health plan (which focuses on prevention). I’m convinced these strategies will influence real change for people with dementia.

If I focus on dementia, I must mention the Alzheimer database. Data is very important for improving our policies and allowing epidemiological monitoring of dementia. Therefore, we will transform our Alzheimer database into a tool for epidemiologic surveillance of dementia. With this project, which will connect the Alzheimer database with the Health Data Hub, dementia is once more a pioneer for our policies.

And of course, in the fight against the COVID-19, we never forget the most vulnerable. People with Alzheimer’s, especially those leaving in long-term care settings, are extremely vulnerable to COVID. They’re a priority in the struggle against the pandemic.

At a European level France led the way in making dementia a European policy priority – do you foresee France raising the issue once again during its EU Presidency in 2022?

France has been very active in the last twenty years. In 2000, France was one of the first countries to launch an Alzheimer’s plan. The first European Joint Action on Dementia was led by France (by the Haute Autorité de la Santé) and involved 30 partners from 19 European countries. On 17 December 2008, at the end of the French Presidency of the Council of the European Union, Employment, Social Policy, Health and Consumer Affairs Council meeting adopted “Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer’s disease”.

The policy landscape has changed dramatically during the last 20 years and we have seen considerable progress as both national governments and the EU have given dementia greater prominence within their health and research policies. The awareness of the burden dementia means is now shared among European countries. Most of European countries now have a dementia strategy. Dementia remains a priority, but it can be mainly addressed within other policies relating to chronic diseases, mental health or ageing.

As the population continues to age, the number of people living with dementia is increasing. Therefore, France is and will remain very active in Europe. We will, for example, continue to take part to European dedicated initiatives such as the JPNP, the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. We will also participate and support the European Group of Governmental Experts on Dementia which provides a platform for the exchange of good practice between countries and I will consider signing the memorandum of understanding to indicate my support to this initiative from Alzheimer Europe.

But it’s time to renew the approach of dementia in our politics. France is convinced that new steps towards a more concrete Europe of health are necessary and will continue to promote it very strongly.”

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But it’s time to renew the approach of dementia in our politics. France is convinced that new steps towards a more concrete Europe of health are necessary and will continue to promote it very strongly. It’s the way we will together make progress in the next year.
On 17 of December, we met collectively for the first time with the government regarding the creation of a neurodegenerative roadmap 2021–2022, which we hope will be politically and financially supported to allow:

- The inclusion of neurodegenerative issues in existing or forthcoming policies (e.g. the much-awaited autonomy law)
- Support for the implementation of concrete actions to answer the specific needs of people living with dementia and caregivers.

We hope this roadmap will be ready for April 2021.

What do you consider as the areas of policy relating to dementia which require the greatest prioritisation?

A lot of subjects related to Alzheimer and related diseases still require structural and financial efforts, including:

- Supporting dementia research
- Strengthening existing facilities
- Improving post-diagnostic support
- Timely diagnosis
- Targeted prevention measures
- Improving diagnosis, care and support for people with young onset dementia.

Moreover, the experience of people living with dementia and caregivers this year during the pandemic also revealed our biggest failures as a society and we need to collectively respond, including:

- Recognising dementia as a disability
- Supporting caregivers
- Raising societal awareness of the condition and its impact on the well-being of people living with dementia and caregivers
- The importance of the non-medical approaches.

In 2022, France will take on the Presidency of the EU – how would you like to see dementia included in its work during these six months?

As more and more dedicated strategies are signed in several European countries, I think there’s a rising consciousness on the impact of inaction in this area.

Neurodegenerative diseases represent a global challenge for our societies. If we don’t react now, the consequences will be dramatic for people living with dementia and caregivers, as well as for our health systems and the economic and social sectors.

For France Alzheimer, the French Presidency of the EU could be an opportunity to raise awareness and to give a strong political impetus to a shared European vision and ambition. We already raised the matter with the first health advisor of President Emmanuel Macron on this specific subject and will continue our advocacy this year.

France is a little more than one year away from the Presidential elections – what bearing does this have on your policy work?

Beyond the development of the roadmap, we believe there is an opportunity to bring back Alzheimer’s issues on top of the political agenda during the next presidential campaign in 2022.

We have therefore already started engaging with French deputies in January. We feel that with the work we undertook in 2020, as well as the creation of a specific Alzheimer’s study group in National Assembly, the political landscape will respond positively to our advocacy.

France must not give up on a dedicated national Plan:

- To meet the ambition of the WHO’s Global Action Plan on Dementia 2017–2025
- To bring concrete answers to the rising number of people living with dementia and caregivers.
The Alzheimer Society of Ireland reflects on campaign to secure dementia funding in government budget

As the Irish Government commits to spending EUR 13 million on dementia, Avril Easton, Advocacy Manager with The Alzheimer Society of Ireland (ASI), reflects on this positive development and their campaigning work leading up to the announcement.

In October 2020, The Alzheimer Society of Ireland (ASI) welcomed the Irish Government’s decision to invest EUR 13 million in dementia community supports in Budget 2021. This was a welcome step in dealing with the sharp deterioration in health of both people with dementia and their family carers caused by the COVID-19 pandemic.

The ASI’s Pre-Budget Submission 2021, ‘Dementia: The Forgotten Crisis’ outlined the detrimental impact of COVID-19 on people affected by dementia and the continued absence of vital services and the growing gap between need and delivery which is now more critical than ever.

A key element of the overall Budget campaign was our strong working relationship with the National Dementia Office (NDO) and the All Party Oireachtas Group on Dementia. Together we identified the key issues that needed to be addressed to combat the challenges facing people with dementia and their families.

As a result of this combined effort, the EUR 13 million investment announced included four key Budget asks:

1. EUR 5 million investment for community dementia supports, this includes EUR 2.5 million for The ASI to further expand our day care in the home service and other community supports
2. EUR 7 million to provide 250,000 hours of dementia appropriate home care
3. Funding of nearly EUR 1 million to recruit an additional 11 Dementia Advisers in 2021 (bringing the total to 30 in place by end of 2021)
4. EUR 127,000 for the Dementia: Understand Together Community Activation programme with funding support for a National Coordinator and a Programme Support Officer. There is more about this combined effort from the National Dementia Office perspective later in this article.

Budget 2021 marked another critical step in the understanding at Government level of the harsh realities faced by people affected by dementia. Research undertaken by The ASI at the height of the COVID-19 crisis in 2020 highlighted that 86% of family carers were concerned about a decline in their loved one with dementia, while 61% of family carers believe their own mental health has been negatively impacted. People with dementia and their families are worried, stressed and fearful due to the continued closure of key face-to-face community services such as day care centres.

Another key component of the campaign was the contribution from full-time family carer Denise Monahan who highlighted how challenging it has been caring for a loved one with dementia during COVID-19. Denise wanted the Government to know how critical it was that investment was provided to reopen dementia-specific services such as day care. Denise’s father, Seamus, was diagnosed with Alzheimer’s eight years ago and has attended The ASI’s Rose Cottage day care centre in Dublin since his diagnosis. However, the lockdown and closure of Rose Cottage has proved very challenging for Seamus and the whole family.

"Usually on Budget Day, people with dementia are totally forgotten about, but it was great to see people with dementia and their family carers not being taken for granted. Just to hear the word dementia being mentioned gave me a lift. It’s so important that people like my father – and the thousands of others around the country – have the support they need and deserve. Dementia is a very tough journey and families need all the support they can get."

Denise Monahan, full time carer
Despite the fact we were not able to lobby politicians in person we ensured that our TDs and Senators were aware of the issues that needed investment in Budget 2021. Over 60 people including 30 members of Parliament attended our Virtual Launch Live Webinar, ‘Dementia: The Forgotten Crisis’ in late September. We also had great support from the All-Party Oireachtas Group on Dementia which mirrored our asks in their Pre-Budget Submission.

We also worked closely with the National Dementia Office around the development of the Dementia Adviser service, which, we identified as an important service for people with dementia and their families that needed national coverage. We all recognised that no one organisation holds all the answers to tackling dementia effectively and that the lived experience was instrumental in informing the evidence-base; not only supporting the work but also directing it.

Following the Budget announcements the work still continues to ensure that these investments positively impact on people with dementia and their families as soon as possible. The ASI has met with Minister for Health Stephen Donnelly to discuss progress and further meetings will be held in 2021.

For more information on The ASI’s Pre-Budget Submission 2021, go to https://www.alzheimer.ie

Budget 2021 represents a good package to support people with dementia and their family. We have waited for some time for these investments and they are so badly needed. This is the first time a Budget has included dementia in this way and that is recognition for such a significant disease and its impact on thousands of families. I just hope that is the real start of a continued cycle of adequately supporting people with dementia and their families in Ireland.”

Pat McLoughlin, Chief Executive, The Alzheimer Society of Ireland

Key highlights of Budget 2021 affecting people with dementia

- 5 million hours of home care announced (minimum 5% ring-fenced for people living with dementia which equates to 250,000 hours)
- Expansion of in-home day care service provided by The ASI
- Expansion of the Memory Technology Resource Room Network
- 4 new memory assessment and support services across Ireland
- Recruitment of 11 Dementia Advisors in 2021 (30 Dementia Advisers in place by end of 2021)
- Education for staff in the acute hospitals about dementia and delirium care
- Implementation of the National Clinical Guideline on Appropriate Prescribing of Psychotropic Medication for non-cognitive symptoms in people with dementia
- Dementia: Understand Together in Communities funding for the recruitment of a National Coordinator and a Programme Support Officer
- Carers Support Grant increased by EUR 150 up to EUR 1,850
- Increase in the dependent relative tax credit from EUR 70 to EUR 245 for family carers.
Future direction of EU policy emerges as series of agreements reached at the end of 2020

As 2020 drew to a close, the EU finalised a number of internal and external agreements, setting out the future policy direction of the EU over the years ahead. In this article, Alzheimer Europe examines some of the relevant details from the Multiannual Financial Framework (MFF), EU4Health programme and Horizon Europe research programme, as well as the trade deal negotiated between the EU and the UK.

Multianual Financial Framework and Next Generation EU

On 17 December, following the European Parliament’s consent, the European Council adopted the regulation laying down the EU’s multianual financial framework (MFF) for 2021–2027.

The regulation provides for a long-term EU budget of EUR 1,074.3 billion for the EU27 (in 2018 prices), including the integration of the European Development Fund. In addition, the Next Generation EU recovery instrument provides an additional EUR 750 billion, allows the EU to provide an extensive funding package over the coming years, supporting Member States to recover from the COVID-19 pandemic, as well as helping the EU to achieve its long-term priorities across different policy areas.

The next long-term budget will cover seven spending areas, covering almost 40 EU spending programmes in the next seven-year period. The majority of these sectoral EU funding programmes are expected to be adopted in early 2021 and will apply retroactively from the beginning of 2021.

EU4Health programme

On 14 December, the European Parliament and the Council of the EU agreed a deal in relation to the EU4Health programme, as part of the MFF, confirming a total dedicated budget of EUR 5.1 billion (in 2018 prices) for the programme, in part supported by “top-ups”.

The new programme will support actions across a range of health policy areas, including investing in health promotion and disease prevention measures, as well as preparing European healthcare systems to face future health threats.

The programme will provide support to Member States to develop healthcare standards at the national level, as well as supporting communication activities which promote disease prevention and healthy lifestyles, as well as countering misinformation.

In response to the COVID-19 pandemic, the programme will support actions which foster the production, procurement and management of crisis-relevant products in the EU, in order to make them more available and affordable.

The Parliament and Council have also agreed that 20% of the total budget should be reserved for health promotion and disease prevention, which address health risks. Furthermore, the digitisation of healthcare, including the creation of a European health data space, is also part of the agreement.

In addition, other EU programmes will provide additional support and investment in health to complement the EU4Health programme, including:

- European Social Fund Plus (ESF+) to support vulnerable groups in accessing healthcare
- European Regional and Development Fund to improve regional health infrastructure
- Horizon Europe for health research
- Union Civil Protection Mechanism/rescEU to create stockpiles for emergency medical supplies
- Digital Europe and Connecting Europe Facility for creating the digital infrastructure needed for digital health tools.

More information on the EU4Health programme can be found at: https://ec.europa.eu/health/funding/eu4health_en
Horizon Europe research programme

On 10 December, political agreement between the European Council and Parliament was reached, a pivotal moment in the commencement of the Horizon Europe research programme, ostensibly, on 1 January 2021.

The final total budget agreed for the programme (formalised by the passing of the budgets of the MFF and Recovery instrument) is EUR 84.9 billion (in 2018 prices), of which EUR 5 billion will come from the recovery instrument.

This will include a dedicated health cluster under “pillar two” of the EU’s approach to implementation of the programme. Additionally, it is expected that there will be a follow-up partnership programme to the Innovative Medicines Initiative (IMI) Joint Undertaking, through the European Partnership for Health Innovation/Innovative Health Initiative, however, details of this have not yet been finalised, at the time of writing.

The next steps will be for the Commission to finalise a number of foundational steps, including negotiations to finalise the associate countries and the terms under which they will be able to contribute and collaborate as part of the programme. The Commission will then create a work programme, as well as publishing a call for research submissions.

You can read more on the Horizon Europe programme at: https://ec.europa.eu/info/horizon-europe_en

EU and UK finalise “Trade and Cooperation Agreement”

On 24 December, the United Kingdom Government and the European Union announced the finalisation of the “EU-UK Trade and Cooperation Agreement” setting out the future relationship between the two, in relation to trade and a number of EU programmes.

Of greatest interest and relevance for dementia policy, is the future relationship in relation to the Horizon Europe research programme (2021–2027), to which the UK will retain access, albeit under less favourable terms than during the UK’s membership of the EU and participation in Horizon 2020 (the previous research programme).

Under the Agreement, the UK will retain its ability to contribute and participate in the programme, as an Associate Member of the programme, and will be able to apply for top tier membership which would allow it to continue coordinate research within Horizon Europe. However, the agreement does not finalise all details of the UK’s association with the Horizon Europe programme and further negotiations will be required to formally “associate” with the programme.

The UK’s annual pay-in to EU programmes will be calculated based on the country’s gross domestic product as a share of EU GDP. A further sum, the participation fee, will be levied at 4% of the country’s operational sum. This contribution may be adjusted upwards or downwards “retrospectively”, depending on the level of funding received by the UK, compared to its contribution. The UK will also receive money in return should its researchers be excluded from any aspects of the Horizon Europe programme.

The UK will have the right to participate as observers in the board of governors of the Joint Research Centre, however, it will not have voting rights. Additionally, the UK will remain in the European Research Infrastructure Consortium programme.

Separate from the provisions relating to Horizon Europe, UK citizens will lose the right to travel, work, study or reside in the EU for as long as they wish. For UK researchers, visas will now be required for stays of over 90 days in the EU. Furthermore, the UK will no longer participate in the EU’s Erasmus+ university exchange programme.

The full text of the Agreement can be read here: https://ec.europa.eu/commission/presscorner/detail/en/ip_20_2531

Key programmes, such the Horizon Europe and EU4Health, have seen their budgets “topped up”
European Group of Governmental Experts on Dementia meets online to update on latest dementia policy developments

In its final meeting of 2020, the Group met online to discuss the latest developments relevant to dementia policy, including national dementia strategies, as well as the emerging evidence and data about the impact of the COVID-19 pandemic on people with dementia.

The European Group of Governmental Experts on Dementia has held its final meeting of 2020, connecting online to exchange updates and knowledge on the most recent and relevant developments in relation to dementia.

The meeting was attended by representatives of 18 countries, Austria, Belgium (Flanders), Czech Republic, Estonia, Finland, France, Germany, Iceland, Ireland, Italy, Israel, Latvia, Netherlands, Norway, Poland, Slovenia, Switzerland and the United Kingdom (England). Representatives from the European Commission (DG SANTE) and the World Health Organisation (WHO) were also present at the meeting.

National and international dementia policy developments

In the first section of the meeting, the group heard presentations in a number of areas related to progress on national and international policy areas. This included:

- An update on the publication of Dementia Plan 2025 in Norway, the country’s third national dementia strategy (see an interview with the Norwegian Health Minister on pages 22–24)
- Details on a recent large-scale epidemiological study in Norway, examining the prevalence of dementia in the country, which suggested that the numbers were even higher than those estimated by Alzheimer Europe in its 2019 Yearbook
- Confirmation of the publication of a new Dutch National Dementia Strategy which will run from 2021–2029, building on the work of previous strategies in the Netherlands
- Developments in relation to a replacement for the French Neurodegenerative Disease Strategy which concluded in 2019 (see an interview with the French Health Minister on pages 25–27)
- The WHO’s ongoing work to deliver on the Global Action Plan on Dementia, as well as recent developments at the 73\textsuperscript{rd} World Health Assembly, including the resolution proposing global actions on epilepsy and other neurological disorders.

The impact of COVID-19 on people with dementia

In relation to the ongoing COVID-19 pandemic and its effect on people with dementia and their carers, the group heard from a number of speakers.

Adelina Comas-Herrera of the London School of Economics, whose research has focused on the impact of the pandemic in relation to long-term care services, as well as working on the long-term care COVID website (https://www.ltccovid.org), a repository of resources and evidence focused on COVID-19 across care settings. In addition to outlining the disproportionate mortality rates associated with dementia and COVID-19, it was also highlighted that measures to protect care homes had been largely ineffective, whilst the effects on the mental health and wellbeing of individuals had been negatively impacted. As a whole, the need for better data in community settings, as well as the need for governments to address structural weaknesses in long term-care was emphasised.

The Italian Institute of Health presented emerging data about the effect of COVID-19 in Italy, specifically highlighting the higher mortality rate amongst people with dementia who contracted COVID-19, the data demonstrating the worsening of symptoms associated with dementia, as well as the atypical presentation of the virus in people with dementia. In addition, it was highlighted that a development of a resource published by the Italian Dementia National Plan Working Group aimed at safely supporting people with dementia in different care settings, which would be provided to dementia services, GPs and other healthcare professionals.

The Dementia Expert Centre in Flanders shared some of the lessons learned, particularly in relation to the importance of reducing isolation and loneliness in people with dementia and carers. It was highlighted that a taskforce on COVID-19 had been established, with working groups examining issues such as guidelines and psycho-social care. Furthermore, the need to address support for people with dementia living at home, as well as the importance of advanced care planning, were also highlighted.

During the open discussion, some members were able to outline the approach of their respective countries in relation to the roll-out of a vaccine, with some indicating that people with dementia in their countries would be included in the first groups of the people vaccinated.

The next meeting of the group is expected to take place on 15–16 June 2021.
Living with dementia during COVID-19

Idalina Aguiar and Nigel Hullah are members of the European Working Group of People with Dementia (EWGPWD) and Kevin Quaid is Vice-Chairperson of the group. In this article, they share different aspects of navigating the COVID-19 pandemic and its associated restrictions.

Kevin Quaid (Ireland) – Living with COVID-19

When people who are diagnosed with any progressive and incurable disease decide to become an advocate, then you know that there is a lot of fight in them. Some people don’t become advocates and try to go it alone, and that doesn’t make them any less of a fighter. Everyone is fighting their own battle and now the whole world is fighting a terrible enemy together, called COVID-19. I can only tell you how I have managed to stay ahead of it and keep safe from it, while living in Ireland.

“Lewy Body Dementia Survival and Me”

Approximately four years ago, I was diagnosed with Parkinson’s disease and then, a number of months later, I was diagnosed with Lewy body dementia (LBD). I spent the next three years searching for answers – it took a while for the diagnosis to become ‘real’ in my head. I am lucky that my wife, Helena, has a brilliant understanding of medicine and it didn’t come as a surprise to her that I had LBD, but when I heard it, my first reaction was that my memory was fine so how could I have dementia? That led me to research, which in turn led me to a love of writing and, to my surprise, I became one of the first people in the world to write a book about LBD from the patient’s point of view. The book is called “Lewy Body Dementia Survival and Me”. Little did I know that this new life, with dementia, would help me through the COVID pandemic! With the support of The Alzheimer Society of Ireland and the European Working Group of People with Dementia (EWGPWD) and the work we do on patient and public involvement (PPI) in research, I am able to keep active and I am able to keep some sort of structure in my life. I never knew that I could, or ever would, become a writer, but after I launched my first book, a paper approached me. I now write a weekly article for them, mostly about dementia.

Life under lockdown

To give you a better picture of my life; I live with my wife and full-time carer, Helena, in the middle of the countryside, about three miles from our local town, Kanturk, in County Cork, Ireland. Living here has been a life-saver for us in a lot of ways, in that we don’t meet a lot of people and, indeed, during the lockdown in January 2021, the rules in our house are quite simple: no one in and no one out. My advocacy work and the fact that I am involved in so much research means that I attend a lot of online meetings with different organisations. Before lockdown, my son and son-in-law turned part of a small workshop that I had, into an office, so when I get up in the morning, I have my breakfast and get ready for work, as I call it, and go to my office. There’s a fine line between forcing yourself to do something and being just lazy, but most days I seem to get it right.

I love sports and among my favourites is horse racing. I have some friends who are...
We try to set an example, and show that greeting others by touching elbows only.

During my daily activities at the day care centre have been unable to, due to the pandemic, as most centres had to close. People with dementia who normally attend day care units, were unable to see family members, which could compromise their care.

The most important thing is not to be alone and not to be isolated. I, like everyone else, miss the social interaction with people and I miss going for a pint of Guinness, but if I do the right thing now, and people who I know and love and care about do the right thing – staying at home where possible; keeping our hands washed and keeping our minds busy – we will hopefully get the vaccine and get rid of COVID-19, so we can get back to a normal life and a good pint of Guinness!

Please stay safe.

Idalina Aguiar – Portugal

Living with dementia and caring for a person with dementia is very demanding and the new coronavirus pandemic is especially hard on us, particularly when people are older and have a neurodegenerative disease such as Alzheimer’s or another type of dementia, because this makes them more vulnerable to COVID-19. Since people with dementia are much more likely to contract the disease, because they have very limited access to or understanding of reliable information about the pandemic, they may have difficulties in understanding the message and in remembering the preventive and safety measures (e.g. wearing a mask and frequently washing hands).

People like me, who are more vulnerable to the virus, are also deeply affected by the change in their important routines: going out for a walk, spending time with family, neighbours and friends, attending a day care centre. In the case of people who are living in a care home, restricting family visits has very negative consequences. Social isolation is very harmful for them. Providing psychosocial support for people with dementia and their carers is essential and urgent, in order to protect them from the impact of this pandemic.

During my daily activities at the day care centre I attend, we were the ones who set the example, wearing masks, ensuring our hands were always clean and, above all, greeting others by touching elbows only. We try to set an example, and show that our memory problems need not prevent us from protecting ourselves, as long as we get used to these new routines.

The day care centre I go to is called “Lugar de Memórias”. It is part of the “Garouta do Calhau” community association. Users of the centre have different types of dementias and the centre affords all of us different supports and activities. Despite the lockdown, they where always with us in online sessions such as yoga, music therapy, cognitive stimulation, occupational therapies and physical therapies, as well as a multitude of recreational activities such as dance, gardening and intergenerational exchanges. All these activities are adapted to suit everyone who attends, and everyone smiles, helps and participates. Incredible work has been done to cater for people who may otherwise have struggled to remain engaged and connected to others during this difficult period. The challenges are constant, but they are accepted by the professionals who work with this small community of people with dementia.

Today, the centre and its activities are very sought after, among the population affected by dementia and their families. The multi-faceted team that makes the most of its professionals, including many assistants alongside various specialists (psychologist, social worker, psychomotricist, music therapist, social animator, and occupational therapist). I am very grateful for the good work they are doing to support us.

Idalina celebrated her 80th birthday during the first COVID lockdown in Portugal, with her daughter Nelida

I have found several ways to live with my dementia during the pandemic. While in lockdown, my daughter and I created an online group in which we shared experiences and discussed complementary therapies. I also tried my best to do everything I was used to doing at the day care centre, to ensure I remain as active as I can, with the essential help of my family.

People with dementia who normally attend day care centre have been unable to, due to the pandemic, as most centres had to close and leave their users at home. Other people with dementia, who are hospitalised in long-term care units, were unable to see family members, which could compromise their conditions.
mood and recovery. Our project arises from the need to bring some comfort, joy and stimulation to all these people.

The project has been expanded to the national level. We share a variety of videos, for kids and adults, with music, theatre, dance, ballet and other engaging material that prove to be beneficial for the participants.

We have come together to try to improve things, not just for ourselves but for others like us, adapting to this new way of life.

Our motto is: “Laughter is the music of the spirit”.

I also do yoga and meditation, because I find them beneficial for my mind and body. Although it requires commitment, persistence, enthusiasm and energy, but, and needs to be practiced frequently, with assiduity, effort and discipline, I believe that yoga is for everyone.

I believe that, while some aspects of advancing age, dementia and co-morbidities are inevitable, others can be avoided with regular yoga or meditation practice. It is important, however, to seek the guidance of a teacher who can adapt the practice according to individual needs.

In summary, while people with dementia can sometimes be apprehensive and anxious in unknown situations, such as this pandemic, this can be managed by maintaining daily activities or adding others more adapted to the safety and comfort of home. Practicing yoga, meditation, dance, art, cooking; or other activities helps us to find some inner peace and to deal with the present moment in a more balanced and calm way.

Nigel Hullah (United Kingdom – England and Wales) – Webinars during COVID

As Chairperson of the 3 Nations Dementia Working Group (3NDWG), I have played a role in helping deliver a series of webinars, recently; some of which have been around the impact of COVID-19 on people affected by dementia. The webinars have been well attended and supported. They have generated a lot of discussion, the panel members have been a mix of professionals, carers, and people with lived experience of dementia.

The webinar structure and content are designed and delivered by people with this lived experience, so the evidence and contributions are what matters to the 3NDWG and its wider membership. There is a mechanism in place for the wider membership to suggest themes and subjects for the webinars. Participants in the webinars are encouraged to post comments in the chat boxes and to reach out and make connections. These chat boxes are particularly busy, which is a real success of the webinars.

We also facilitate Saturday/Sunday social meetings for members, and these have proved popular. The format is more relaxed than the webinars, with no agenda – just an hour of chat and friendship, allowing people a break from lockdown and giving them the opportunity to connect. All of these activities are hosted via the Zoom virtual application.

**So, what have we learned?**

As well as being united against dementia, we now find ourselves united against COVID-19. So many members are steadfast in following lockdown guidelines and being responsible, to make sure they are staying safe. However, many people have reported concerns over a loss of skills, due to isolation: a loss of acquired skills, both social and adaptive, and becoming estranged from friendships and contacts due to lack of regular engagement; a loss of independence, and having to re-learn how to complete many activities, such as using public transport and traveling independently, either to events, or to do the shopping, for example.

The stress of a caring role is well understood, but what’s also understood is that caring for someone with dementia brings additional pressures during lockdown. These would include ensuring the availability of medications; food delivery; helping the person with dementia to understand why their routine has changed due to lockdown restrictions. The withdrawal of face-to-face services, although a requirement, is hard to understand for the people affected, and brings an inevitable feeling of abandonment, as well as fear that these services will not be in place after lockdown.

A lack of space for carers to recuperate from the stresses of caring imposed by lockdown requirements is a topic that people felt strongly about. Carers felt that there had been no impact assessment done with them, on the effect of losing support services, and no strategies put in place to deal with their concerns. Participants were concerned about carer burnout and about how much recovery time would be needed to restore the balance and dynamic between carer and loved one/service user. There was an acknowledgment that some “repair work” would be needed. We do not know what the final casualties will be, but there will certainly be more than just medical fallout, and service providers need to understand that many of the concerns that were raised by our members are related to people with dementia being anxious about resuming activities, post lock-down. The
support that was available, pre-COVID-19, will still be needed, post-COVID.

It was also made clear to us, in comments from webinar participants that, after the easing of restrictions, we will need careful thought about how re-engagement happens. It will need be at an agreed pace, not one driven by expediency. Many participants felt that they might be more reliant on their carers as they adjust back into routines. To allow for this, it was felt that we would need to rebuild confidence in one another and in the available services. It was also felt that the third sector (voluntary/non-profit sector) could be vital, and that organisations such as the Alzheimer’s Society, Dementia Friends, the Dementia Engagement and Empowerment Project (DEEP), among others, may be pivotal in helping people through the readjustment phase.

**Conclusions**

Health and care workers, and third sector organisations continue to play an especially important role in supporting and protecting the rights of people living with dementia in the UK, during this public health crisis.

Worrying practices have been reported by different media sources and in different geographical locations across the UK, including: refusing hospital admission to people living with dementia; a lack of antigen testing for those either living or working in care homes (or those moving in); a lack of personal protective equipment (PPE) in care homes, and the mass signing of DNAR (do not attempt resuscitation) forms.

Professionals and the voluntary sector have spoken out about the effects of the pandemic and of these worrying practices, and are working to mitigate them. Emerging evidence points to extremely high levels of vulnerability to serious illness or death from COVID-19 among people living with dementia, and shows that this may be under-recognised. The effects of prolonged lockdown or of post-COVID hospital discharge needs further investigation.

Overall, it is clear that dementia care in the UK has been negatively impacted at many levels by the COVID-19 pandemic.

This is just a very brief overview of themes and issues arising from the 3NDWG webinars. For further information or engagement on these and other issues, the 3NDWG is happy to engage, on Twitter(@3NDWG), or you can visit our website: https://www.3ndementiawg.org/

I want to thank everyone who participated in the webinars and the Saturday/Sunday social meetings, as this allowed us to gather this important information. Special mention must be given to Adele Doherty, Head of Dementia Voice who has worked so hard to make this happen.

It is likely that these webinars and the Saturday/Sunday social meetings will continue, post-lockdown, as they have proven to be an easy, effective and inexpensive way to connect with the wider membership of the group, and to encourage engagement.
The impact of COVID-19 on human rights

COVID-19 has hit us hard, in obvious areas like health, healthcare systems, the economy, and the way we interact with others, socially and professionally. Perhaps less obviously, it has had an impact on human rights. Alzheimer Europe asked some of its members to discuss the impact of the pandemic on the human rights of people living with dementia and their carers, and to share their responses to this issue.

France: Ethical issues, breaches of human rights and a “lack of common sense”

Facing the great scale of the worldwide pandemic, the French Government has taken several measures to ensure the protection of people. It is for this reason that, inter alia, the politicians decided to suspend visits to nursing homes. When the first lockdown was decided, the government also decided to restrict French citizens’ movements and required an authorisation form to be completed.

Despite the closure of France Alzheimer’s own structures, our network of 99 local branches embarked upon a large-scale mission, to bring support to the families impacted by dementia.

At a national level, France Alzheimer – while aware of the challenges faced and the need to respect security measures – nevertheless listened to and shared the numerous testimonies coming from all over the country, and shared these with the French Ministry of Health. Indeed, our advocacy mission kept on growing as the number of measures, impacting negatively on people with dementia and their carers, increased: social isolation, loneliness, the ban on going out whenever they want and need to, the closure
of services and respite facilities, the sudden cessation of therapeutic activities – the list goes on. The government’s decisions continue to have a significant impact today.

Ethical issues, breaches of human rights and a lack of common sense surfaced during the first lockdown and hit us hard as we tried to denounce these consequences and the distress caused to people with dementia and their families. To name just a few examples:

- the sudden cessation of visits and funerary rites in nursing homes
- the organisation of visits under surveillance and behind Plexiglas, between the two lockdowns
- total “radio silence” around the specific experience of people living with cognitive impairments in nursing homes, and of carers at home
- police fines, sometimes handed down several times per day to the same person living with dementia, because they hadn’t understood why they couldn’t go out
- the impact of not recognising cognitive impairments as a disability (recognising dementia as a disability would have allowed people with dementia to access the same exemptions that were granted to other people with disabilities when going out)
- the difference between consent and assent and its impact on the organisation of Christmas and vaccinations.

Since March, we have been advocating a lot; discussing ethical issues, attending many Zoom meetings, learning a lot about other European associations’ experiences – all of which has provided us with tremendous resources to adapt the way we bring support to people living with dementia and their carers. Sometimes, we win: we are heard; we have a voice; we still feel hopeful. But the current crisis has left no-one in doubt about the flaws in the system – our system; and about the wounds inflicted on our society. We find ourselves screaming: “Never again!”

Portugal: The right to vote comes under threat

In Portugal (as in all other countries), people living with dementia in the community, and especially in nursing homes, are facing strong restrictions on some of their fundamental rights due to the implementation of measures put in place to reduce the spread of COVID-19.

On 24 January 2021, there were presidential elections in Portugal. So, the right to vote, which is included in the fundamental right to citizenship previewed in article 26º of the Constitution, became one of the rights under threat during the pandemic.

People who were in lockdown due to COVID-19 were allowed to vote in advance, and a representative from the municipality visited them in order to personally collect the vote in a sealed envelope.

For patients who are in hospitals, or for people who are in prison, the legislation was recently changed to account for the pandemic, in order to allow these groups of the population to vote by setting up voting booths at hospitals and in prisons. None of these alternatives, however, were initially taken into account in the legislation for people living in nursing homes, including people with dementia maintaining the right to vote.

Even in normal times, living in an institution can present particular problems in exercising the right to vote. Sometimes, the polling station is far from the nursing home, as people may not have updated their official address; people may need assistance in getting there, and there is no one available or there is no accessible transport. People may also be unaware of the importance of exercising their right to vote.

The question is: why, when special measures are being taken to ensure the right to vote for some marginalised or vulnerable groups, are people living in nursing homes not included, given that they are also a marginalised and vulnerable group?

In response to this issue, the National Elections Committee began to say that people who are living in nursing homes would be allowed to go out to vote, without needing to respect the lockdown. But this begs the question, when we know that most care home residents remained in their facilities since March 2020, without leaving even for Christmas (to go out for Christmas meant 14 days of quarantine) and with tight restrictions on visits from family members and friends: is it not, then, a huge contradiction to say that there is no problem to go out to vote?

Many questions have been asked by several organisations representing nursing homes: who will take these people to vote? Will it be their families? Why is there a difference...
between visiting a resident in a nursing home, and taking them to vote? Is there any difference in terms of virus transmission? How can the nursing home staff manage to take residents to vote when they are short-staffed and over-worked as it is?

During the TV debates in the run-up to the presidential elections, the candidates discussed this issue and, fortunately, the Government promised that special teams would visit nursing homes with ballot boxes, to allow people the same access to their right to vote as other vulnerable groups of the population were afforded. An act of the Government covering this and a number of other lockdown measures was urgently passed on 11 January 2021, as the number of people infected and the number of deaths continued their exponential increase.

Alzheimer Portugal is hopeful that this measure will last beyond the pandemic and will give rise to long-term, positive change where the rights of people with dementia are concerned.

Spain: A second pandemic – one of social isolation

Spain was one of the first countries in Europe to experience the full impact of the coronavirus pandemic, imposing a strict lockdown during the first wave that only allowed citizens to leave home to meet essential needs. After lifting these restrictions for a partial re-opening during the summer, the country dipped into a second wave in October, followed by yet more restrictions, including a national nightly curfew and travel constraints within Spain.

The population of individuals over age 65 has been among the hardest hit by COVID-19 globally, owing to the disproportionately high rates of morbidity and mortality in this age group. Furthermore, the numerous restrictions in Spain have caused older people to bear a similar burden of non-disease-related suffering due to the pandemic, and perhaps have fostered a second pandemic – one of social isolation. Spain’s lockdowns, curfews, and restrictions have had stark impacts on the social and cognitive wellbeing of people with dementia and their carers. Notably, individuals with dementia have experienced drastic changes to their daily routines, decreased access to social support and interaction, and a restricted ability to partake in leisure activities. These changes can manifest in devastating consequences, including increased levels of confusion, disorientation, and other neuropsychiatric symptoms.

In addition to the inadvertent toll the coronavirus pandemic has taken on the wellbeing of people with dementia, the human rights of these individuals have been subjected to more deliberate affronts, in that the Spanish Administration did not guarantee these people access to hospital or critical care. The Spanish Society of Intensive Care established, during the first peak of the crisis, that “any patient with cognitive impairment, either due to dementia or any other degenerative condition, will not be eligible to receive mechanical ventilation,” thereby de-prioritising the lives of all patients with dementia, regardless of disease stage or remaining life expectancy. Additionally, as discussions about COVID-19 have been dominating the health, policy, research, and public spheres in the EU, there is a big risk that issues faced by the dementia community will continue to be overshadowed. Many contributions have been made, in the last decade, to research and policy discourse surrounding dementia, but this de-prioritisation due to the pandemic could lead to a halt in, or loss of, that progress.

In order to reduce the deleterious impact that the coronavirus pandemic has had on the lives of people with dementia, Spain must raise the issue of dementia to a level of national priority. Rather than addressing the country’s worsening dementia situation as an isolated problem, the public rhetoric should shift to include dementia as a direct impact of the COVID-19 pandemic, and research into dementia should be considered as related to research about the virus itself. At this time, it is more important than ever to focus social campaigns on reducing the stigma around dementia, so that the struggles of those affected can be addressed more effectively in public policy. Furthermore, flexibility from carers and support organisations is key in maintaining normalcy for those whose lives so depend upon it. Many local organisations have adapted to meet the needs of people with dementia, particularly in highly-populated cities like Madrid and Barcelona, where efforts to lift confinement measures have been markedly slow, even after the outbreak was under control.

Although face-to-face therapeutic sessions have been suspended, Fundación Alzheimer España (FAE) continues to offer cognitive exercises adapted to a remote format, to ensure ease of access for people with dementia and carers. It is clear that, in a country still facing growing uncertainties, the lives of those with dementia require increased attention and accommodation in order to minimise the pandemic’s toll on their wellbeing.
Trust and transparency: patient and participant perspectives on data sharing

In February 2021, Alzheimer Europe published a discussion paper on data sharing in EU research projects on Alzheimer’s disease and dementia. In this excerpt, we address the perspectives of research participants and patients on data sharing, highlighting some of their key concerns.

The invention of the World Wide Web by Tim Berners-Lee in the late 1980’s set the stage for more widespread sharing of research data. By creating tools and pathways for data assessment and exchange, the internet opened new horizons for researchers, catalysing innovation and collaboration on a global scale. The benefits of sharing data from clinical research studies are clear: research can be validated, the returns on investment are increased and, importantly, new hypotheses can be generated by linking datasets from different trials, accelerating scientific innovation. An essential consideration, however, are the perceptions and views of patients and research participants on data sharing.

After all, clinical research data are data about individuals, and often highly sensitive data at that: while researchers are the data generators, the privacy risks of sharing these data are borne almost exclusively by patients and research participants.

Recognising the value and importance of the patient voice, the last two decades have seen a proliferation of studies examining participant and patient preferences for data sharing. In general, these studies show broad support towards data sharing in principle. At a 2017 data sharing summit organised by the New England Journal of Medicine (NEJM), trial participants voiced their belief in sharing data and experiences in order to help themselves and fellow patients, encouraging researchers to look beyond concerns around loss of data authorship and patient confidentiality. A follow-up survey confirmed the willingness of many trial participants to share data. Fewer than 8% of the 771 respondents, from 119 trials at 3 academic medical centres, felt the potential negative consequences of data sharing outweighed the benefits. The desire to help others as much as possible came across strongly in the survey, with several respondents urging greater cooperation and less competition among researchers. An earlier study of participants in the ACT aging and dementia cohort identified scientific advancement, research efficacy and health improvements as important outcomes from data sharing. One participant stated “...to me, the more information researchers have, the better, as long as you [can protect against discrimination]. I mean, that’s what research is, and you’re crippling it by not allowing them to share. And they can’t make advances...if they can’t.” Similarly, a systematic literature review of healthcare consumers found that respondents across studies recognised the importance of research and its benefit to society, and the role that data sharing can play in advancing research. Together, these studies indicate relatively broad acceptance of the principles of data sharing for individual and societal benefit.

Concerns about loss of privacy

But what about attitudes to data sharing in practice? Despite broad agreement on the value of data sharing, patients and participants have voiced concerns about the potential loss of privacy and a perceived lack of transparency in how and when data is shared. These concerns are rarely black and white. Instead, they exist on a continuum that varies depending on the type of data being shared, and the individuals or organisations it is being shared with. For example, systematic reviews indicate high levels of trust in using data from disease registries, which hold clinical data about people diagnosed with a specific disease or condition. The Rare Barometer Data Protection and Sharing survey of 2,013 people living with a rare disease was published by EURORDIS in 2020, revealing that 97% of respondents would be happy to share their disease registry data for research purposes. Similarly, a majority of respondents to a survey conducted with members of the European Leukodystrophies Association agreed with the principle of sharing disease registry data. Conversely, while a 2019 survey of 1,246 hospital patients revealed broad agreement with data sharing in principle, 76.6% of survey respondents identified one or more electronic health record data items they were not prepared to share.

Patients and research participants also hold strong views on who they would like their data to be shared with, particularly when these data are not anonymised. Studies frequently noted a reduced willingness to share data with pharmaceutical companies and insurers, with lower levels of trust in the ethical use of data by these organisations. For example, a 2016 Wellcome Trust survey on public attitudes to commercial access to health data showed that 17% of respondents objected to private companies having access to their health data under any circumstances. Worryingly, a recent survey indicates that data scandals involving organisations such as Cambridge Analytica and Google have damaged public trust in data sharing, with over 25% of US-based respondents stating that they are unwilling to share their health data for any reason. Indeed, trust – or rather, distrust – is a common theme across studies, particularly regarding the potential loss of privacy.

DEMENTIA IN SOCIETY
Listening to the patient voice

As such, it is important not to presume there is a social licence for data sharing. The diverse values of patients, participants and the public should also be incorporated in data governance and sharing frameworks. Indeed, a common theme across studies is the importance of considering the patient voice in debates around data sharing, and the value of involving research participants in decisions on sharing their clinical data. Sharon Terry (a patient advocate and the president of Genetic Alliance) stated “Trial participants are not patients in the traditional sense of the word. It really should be looked at as a partnership.”

A cross-sectional survey of participants in the European DIRECT (Diabetes Research on Patient Stratification) raised a similar point, with over 50% of respondents stating that they would like to be involved in decisions on how and with whom their data should be shared. Going beyond the views of research participants, our 2019 publication, “Overcoming ethical challenges affecting the involvement of people with dementia in research”, discusses how public involvement of people with dementia can contribute to the quality, relevance and ethical conduct of research, including questions around data sharing and governance.

Similarly, a recent report from the British National Health Service (NHS) highlighted the value of engaging with the public (and particularly people from underrepresented groups) to gain a cohesive view of the acceptable uses of health data, and the trade-offs that people are willing to make between sharing data for societal benefit and potential loss of privacy.

Overall, the body of literature on patient and participant views of data sharing reveals a broadly positive picture. However, there are areas of shade amidst the light; although there is widespread acceptance of the principle of data sharing for societal benefit, more nuanced views exist when it comes to what data is shared, and who it is shared with. The benefit of data sharing comes with a privacy trade-off, and the willingness of individuals to accept this privacy risk will vary depending on their perception of the benefit(s). Obtaining and incorporating the views of patients and research participants on data sharing is an important step towards ensuring transparency – and increasing trust.

Acknowledgement

Thanks to support from Gates Ventures, Alzheimer Europe is currently conducting a project on data sharing in dementia research.

transforming AD to protect what makes people who they are
Dementia in Europe

What attracts Early Stage Researchers to the dementia field?

We spoke to six Early Stage Researchers (ESRs) involved in two EU projects, DISTINCT (dementia: intersectorial strategy for training and innovation network for current technology) and MIRIADE (Multi-omics Interdisciplinary Research Integration to Address DEmentia diagnosis), to find out more about what motivates them, and about how COVID is impacting on their research.

Leighann Kimble, MIRIADE

How and why did you become involved in dementia research? What do you enjoy about it the most or what keeps you motivated?

I became involved in dementia research due to my background in health systems strengthening and implementation science. This background led me to continue as an instructor in public health, in which one of the most pressing issues for developed countries includes chronic diseases, mental health concerns, and the health of aging populations. I enjoy dementia research because it provides a means of making discoveries that have important potential significance for the health outcomes of patients. I am motivated by my research focus on data sharing and reuse due to implications in improving research quality, reliability, and reproducibility for future advancements in dementia research.

Tell us about your working day and also about how COVID-19 has impacted on your research and on the wider project?

As a first-year PhD candidate during COVID-19, the majority of my work now takes place online, with most meetings taking place via Zoom. Fortunately, in response to the pandemic, we have become accustomed to advancing our work using online platforms and adjusting research based on feasibility. These adjustments have created a new virtual norm in the working day to minimize any potentially negative impacts on research. For example, the focus of my research will require the use of ethnographic research methods, which I have been able to begin my data collection using online observation and interviews. I look forward to future opportunities for in-person interaction with other members of the project post-COVID-19.

Can you tell us about some of the innovative techniques and technologies you are using?

The focus of my research is on understanding data sharing and reuse as related to innovation. In this work, part of my approach will be to explore open data, open science, and open innovation, which are all innovative and complex topics. To explore these topics within MIRIADE, I will be using ethnographic approaches, which are quite different from the quantitative methods primarily used in the health sciences. I believe this approach will help to add richness to the data and will help to capture the details regarding innovation, with a focus on data sharing and reuse over the course of the project.

What are your hopes for the future of dementia research and how is the project helping to move the field forward?

My hopes for the future of dementia research are that interdisciplinary approaches are continued for future initiatives. Interdisciplinary collaborations help not only to increase efficiencies but are key in transforming our research findings into practice. I would also hope for the increased involvement of patients, which are ultimately the end-users of advancements in dementia research, into future work. Patients are key in sharing their personal data for research and should be heard in the process of research to ensure person-centred solutions in dementia research are considered. The involvement of Alzheimer’s Europe within MIRIADE to provide a patient perspective is a key example of the opportunities and insights that can be obtained by integrating patient involvement.
Viktoria Hoel, MIRIADE

How and why did you become involved in dementia research? What do you enjoy about it the most or what keeps you motivated?

By the end of my first semester in my Masters programme, I was hired as a research assistant at my University in Oslo, working on another cross-national research project evolving around integrated care for older people living in Europe. This is what truly sparked my interest in research – both the national collaboration, but also the close contact with participants, hearing their stories and including them in the improvement efforts. However, in this project, participants were excluded if they had a diagnosis of dementia. If we fail to include this population group when striving to improve the care provision and policy around geriatric care, we miss out on a very important voice when building our future health systems. But to be honest, this is something I did not realise in full before I actually started working in the DISTINCT project. In just one year, my views on social wellbeing have changed, and how I perceive people living with a diagnosis of dementia, as well as their families, has matured.

What I enjoy the most is the warmth and friendliness of everyone involved in this field. Everyone is so open and welcoming, while at the same time having a sober and critical look at how we conduct our research, so as not to forget the individuals that live with a diagnosis of dementia. And the fact that we take on a perspective of how technology can contribute in improving quality of life and wellbeing is really exciting! The world is moving so fast, with so many innovations, that I am truly happy to have a chance to be a part of this development, although my project is just a very small aspect of the progress.

Tell us about your working day and also about how COVID-19 has impacted on your research and on the wider project?

Now I have just concluded some very exciting months collaborating with the World Federation of Occupational Therapy (WFOT), as a part of every ESR’s mandatory secondments. Due to the ongoing pandemic, my “exchange semester” with them has been conducted virtually, but the collaboration together has been great! We managed to publish two articles from our collaboration project, and although they are not directly related to dementia research, the training and experience I gained is invaluable. Now, I can direct my full attention to recruiting participants to my own project, which I will conduct locally here in Bremen, Germany. This will definitely be very challenging during COVID-19, as our collaboration partners in day centres, Support groups and nursing homes are swamped. Also, many participants are not very keen on trying out something new and being in contact with strangers, when we are supposed to keep a safe distance these days. Therefore, we have made training videos that hopefully will be able to help the participants using the technology we are evaluating, as we can’t help them in person, as long as the pandemic is ongoing.

Can you tell us about some of the innovative techniques and technologies you are using?

The technology we are evaluating is known as I-CARE, a tablet-based activation system specifically designed for people with dementia, offering activities adapted to the current needs and preferences of the respective user. The system contains more than 1,000 possible different activities such as games, videos, picture slide shows, stories, etc., all easily available for the user through a recommendation system, that suggests different activities for the user so that they don’t feel overwhelmed with the range of choices. This is made possible by the biography filter supporting the selection of activation content, using machine-learning techniques. The sessions are intended to be completed by the study participant, in tandem with their conversation partner (such as their informal carer or family member), to provide a shared activity that is both engaging and meaningful in itself. I-CARE showed great promise in supporting interaction in the pilot study, however, as the study focused on systems development, no structured assessment of the effects on social health was conducted. This is what we aim to do in a feasibility study, that hopefully will take place early in 2021.

What are your hopes for the future of dementia research and how is the project helping to move the field forward?

My hopes for the future of dementia research and technology developed for this population group, is that it involves the people concerned from an early stage, without the technology won’t be considered too complex nor condescending, but actually useful for the participants involved.
How and why did you become involved in dementia research? What do you enjoy about it the most or what keeps you motivated?

Quality of life is everything. That’s what I learned in my first job as a medical doctor. Fresh out of medical school, I went to work on an old age psychiatry ward in London. There’s no cure for dementia but I was amazed by the difference that positive engagement in social activities could make for the people I was caring for. From sandwich making to singing, it was a joy to remove the power of the disease over the person, even if we couldn’t remove the disease itself.

I got into research because I’m curious, and I’m drawn to trying to solve the really big questions facing society: What are the best approaches to dementia care? And how can we provide the best care in a cost-effective way for the long-term?”

I got into research because I’m curious, and I’m drawn to trying to solve the really big questions facing society: What are the best approaches to dementia care? And how can we provide the best care in a cost-effective way for the long-term? Searching for answers to these questions is what motivates me.

Tell us about your working day and also about how COVID-19 has impacted on your research and on the wider project?

From March to June 2020, my research project was suspended. COVID-19 has put a dent in our progress, because our ability to go out and work with people with dementia has been restricted. I’ve spent most of 2020 working from home, which has some advantages. I can easily concentrate when writing papers and I have much better coffee than the office. There are also challenges though. I’m a very sociable person and I miss the “real-world” interactions, which normally break up a day and can’t be easily replicated: coincidental conversations with colleagues at the coffee machine, for example. These are opportunities to laugh, vent frustrations and maybe get a new take on a problem. I live near a park so now I try to break up the day with a walk, and I regularly join colleagues for informal virtual lunches so that we stay connected.

Can you tell us about some of the innovative techniques and technologies you are using?

Imagine if people with early-stage dementia could learn to use a tablet as easily as a millennial. Tablet-based apps can help people stay socially connected and find new ways to engage in meaningful activities, which could be anything from maintaining hobbies, to playing games, to completing household chores. But how can people with dementia who have never used a tablet learn the necessary digital skills? There are almost 2 million apps in the Apple App Store and almost 3 million in the Google Play Store. How can people navigate all those options to find apps that meet their needs and interests? My team is evaluating FindMyApps, an intervention to help people overcome these challenges. FindMyApps has a unique library of around 300 user-friendly apps, which people can search through based on a personalised profile. A special technique called “errorless learning” helps people learn to use the tablet. The big question is whether or not this improves people’s self-management and social participation.

To find out more about the project, watch this short, animated film (in Dutch with English subtitles).

What are your hopes for the future of dementia research and how is the project helping to move the field forward?

There are so many exciting topics in dementia research. Personally, I’m laser-focused on people – not as patients, but as members of society, living their lives with friends and family, and their own unique personalities. Biomedical research tackling dementia as a disease, through better diagnosis, prognosis and medical treatment is all very interesting. But I think it’s even more exciting – and in some ways more challenging – researching ways in which to support the person living with the disease.

Digital technologies offer great scope to provide support that is positive and personal but also affordable and feasible on a large scale. This is a very new field of research and the evidence base is currently not well-developed. But that’s the great adventure of scientific research: seeing potential, forging ahead into the unknown and discovering new ways to help people live their lives well.
Pascale Heins – DISTINCT

How and why did you become involved in dementia research? What do you enjoy about it the most or what keeps you motivated?

I am one of the fifteen Early Stage Researchers of the “Dementia: Intersectorial Strategy for Training and Innovation Network for Current Technology” (DISTINCT) project. I am currently based at the Alzheimer Centrum Limburg at Maastricht University, the Netherlands. In my research project, I am evaluating the preliminary effects of a mobile application in improving the social participation of people with dementia living in the community.

After completing my Bachelor’s degree, I worked for two years as an Occupational Therapist in dementia care. Next to this, I was enrolled in a Master’s programme where I’ve learned to develop healthcare innovations in interdisciplinary collaboration with other students with a technical or healthcare background. During these two years, I realised that I’d like to be further involved in dementia research. I wanted to be able to increase the independence and quality of life of people living with dementia through the development of new, and the enhancement of existing, healthcare technologies. That’s why I applied for this research project. And that’s what keeps me motivated: being able to make a difference in the daily lives of people with dementia.

Tell us about your working day and also about how COVID-19 has impacted on your research and on the wider project?

My working day usually consists of a lot of computer work in the office and meetings with my research team, colleagues, and collaborating researchers. Next to that, I am taking courses at the University in order to improve my research skills, to gain knowledge in my research field, and to facilitate my professional development. Due to COVID-19, meetings and courses now take place virtually. I have also been working from home for the past few months. As I am currently conducting a literature review and I am not yet including study participants, COVID-19 has fortunately not yet had a major impact on my research project. However, I was planning to do an internship at the beginning of 2021 at Karolinska Institutet in Stockholm, Sweden.

At the moment it is sadly uncertain whether this internship can take place on site.

Can you tell us about some of the innovative techniques and technologies you are using?

During my research project, I will evaluate the preliminary effects of the mobile application Viamigo. The mobile application was developed by the collaborating Transportation Research Institute (IMOB) of Hasselt University, Belgium. It was originally developed for people with intellectual disabilities. The application could help people with early stage dementia to accomplish a known individual route, so that they can independently participate in social activities (e.g. visiting a friend, going to a day care centre, doing grocery shopping, etc.), while a personal coach (e.g. an informal carer) monitors the person in real-time at a distance through the ‘Viamigo’ website or mobile application.

What are your hopes for the future of dementia research and how is the project helping to move the field forward?

More research is needed regarding technological interventions that target social participation in dementia, as social isolation is a common health issue among older adults and a higher participation in social activities is associated with a better quality of life and well-being in people with dementia. I hope that this project will highlight this need. The results of this research project will provide guidance for further research and will be used to adapt the mobile application, if necessary, for future implementation.

You can find more information about me and my project on: https://www.dementia-distinct.com/project/esr11/. If you have any questions, please feel free to contact me by e-mail: p.heins@maastrichtuniversity.nl
Ekaterina Mavrina, MIRIADE

How and why did you become involved in dementia research? What do you enjoy about it the most or what keeps you motivated?

Dementia is quite a personal issue for my family. I witnessed appalling changes in the behaviour of my both grandfathers. I am also aware of the fact that dementia could be inherited, so, my parents and I are in the risk group.

it was fascinating to discover a project where I would obtain the first-hand evidence on how multidisciplinary researchers collaborate, which bottlenecks they face and what helps them make advancements towards the discovery of dementia biomarkers.”

I studied economics and management before joining MIRIADE project. When I decided to do a PhD I really wanted to contribute to the socially relevant causes. However, there are paucity of such projects available to social scientists. Thus, it was fascinating to discover a project where I would obtain the first-hand evidence on how multidisciplinary researchers collaborate, which bottlenecks they face and what helps them make advancements towards the discovery of dementia biomarkers.

Tell us about your working day and also about how COVID-19 has impacted on your research and on the wider project?

As I was saying, in my project I aim to study collaboration, coordination, and their evolution in MIRIADE. Thus, my primary tasks are observing participants during online meetings, online interviewing, analysis of shared data, literature review. I work from home 99% of the time. Luckily, most of these tasks could be conducted online.

To be honest, I am concerned if the quality of interviews might suffer because they would be done online. Another considerable implication of COVID-19 is that I am confined to my studio and cannot explore Amsterdam where I moved 2 months ago from a different country (I am Russian, I lived in Spain for 4 years before moving to the Netherlands in November 2020). This lack of interaction really makes me feel vulnerable and to some extent socially excluded due to pandemic.

Can you tell us about some of the innovative techniques and technologies you are using?

As far as the techniques and technologies go, I would not impress you that much as the applied scientists could. My goal is to combine quantitative and qualitative methods in my research. Thus, digital technologies, like Zoom/Skype, cloud services enable me to conduct participant observations, interviews, and access shared data.

Moreover, I also use such software as RStudio for the analysis of quantitative and textual data. In fact, I will need to master the analysis of unstructured textual data, which I am really looking forward to! Nowadays, more and more unstructured textual data become available and I would like to harness the methods that would allow me to organize the myriads of data!

What are your hopes for the future of dementia research and how is the project helping to move the field forward?

I have great hopes that MIRIADE researchers would be able to make a great leap towards the discovery of the biomarkers of dementia. I would also like to believe that the results obtained through the collaboration of multidisciplinary researchers would serve as an input to companies engaged in subsequent testing and that it would yield successful outcomes.

My greatest aspiration is that the research community would be able to find the definitive early signs of dementia. In this way, people in the risk group would be able to take preventive measures as early as possible and thus delay destructive consequences of dementia progression, staying mentally healthy longer and having more peaceful years with their beloved ones.

What do you enjoy about it the most or what keeps you motivated?

Ekaterina Mavrina

"To be honest, I am concerned if the quality of interviews might suffer because they would be done online.”

"I have great hopes that MIRIADE researchers would be able to make a great leap towards the discovery of the biomarkers of dementia.”

"My greatest aspiration is that the research community would be able to find the definitive early signs of dementia. In this way, people in the risk group would be able to take preventive measures as early as possible.”
How and why did you become involved in dementia research? What do you enjoy about it the most or what keeps you motivated?

During my studies of Biotechnology in Germany, I discovered my interest in medical related research fields. I first became involved in dementia research with the start of my PhD at the Amsterdam UMC in July 2020, where I joined the group of Charlotte Teunissen. I am very grateful to have found this position within the MIRIADE (Multi-omics Interdisciplinary Research Integration to Address Dementia diagnosis) consortium. My project is focused on the development of novel immunoassays for the diagnosis of Dementia with Lewy bodies (DLB) in cerebrospinal brain fluid (CSF) and blood. A great motivation for me has been connecting with those diagnosed with different kinds of dementia, helping me to better understand the impact our work can have on another person’s life.

Tell us about your working day and also about how COVID-19 has impacted on your research and on the wider project?

A typical working day changes during the course of the PhD programme. At the beginning, my days mainly consisted of reading scientific literature to generate the necessary background knowledge to help me navigate my way into my current project. Reading scientific articles is still a big part of my day, but I also manage my own experiments which require planning and ensuring all the necessary materials and reagents are prepared. Depending on the experiment, it can take me a few minutes to a few hours of lab work. During incubation times, I analyse data from previous experiments, summarize results and findings into scientific publications or have meetings with my colleagues (currently online), where we discuss our results or literature.

Unfortunately, due to COVID-19, our laboratory capacities are very limited. This means that during the last few weeks, I had to focus on office and paperwork and couldn’t continue with my experiments for the immunoassay development.

Can you tell us about some of the innovative techniques and technologies you are using?

The general approach to detect specific biomarkers in the respective body fluid is by using specific antibodies that can bind to the biomarker and, through an enzymatic reaction, generate a signal that is measured and used to calculate the biomarker concentration. In an enzyme-linked immunosorbent assay (or ELISA) this can be achieved without expensive machines, but it requires more manual work than other methods. Sometimes, ELISAs are not sensitive enough to detect very low concentrations of the biomarkers. The highly sensitive single molecule array (Simoa) technology, which was developed by Quanterix, combines the analysis of single molecules with a digital ELISA readout. This way, we are able to measure very low levels of the biomarker in an automated way, with reduced hands on time of the researcher.

What are your hopes for the future of dementia research and how is the project helping to move the field forward?

In general, I hope that there will be more breakthroughs in dementia research in the upcoming years, not only in our project focusing on the diagnosis but also in treatment research. Ideally, my colleagues from the MIRIADE consortium and I will find several biomarkers for different types of dementia and develop highly sensitive and specific immunoassays for their detection. The detection of these biomarkers in blood would promise a less invasive process for the patients and facilitate the early differential diagnosis of dementia.
Behind the headlines: Does Souvenaid improve cognitive performance in early Alzheimer’s disease?

In November 2020, the three-year results from the European LipiDiDiet study were presented at the 13th Clinical Trials on Alzheimer’s Disease conference. The results indicate benefits of multinutrient intervention in early Alzheimer’s disease. Cindy Birck of Alzheimer Europe takes a closer look at the study and asks Professor Tobias Hartmann, coordinator of the European LipiDiDiet project, to comment.

LipiDiDiet is a research consortium that studies the preclinical and clinical impact of nutrition in Alzheimer’s disease. This research resulted in experimental dietary interventions, which contributed to the development of the medical food Souvenaid, by the company Nutricia Advanced Medical Nutrition – the specialised healthcare unit of Danone. Souvenaid is a nutritional drink containing an active ingredient called Fortasyn Connect – a combination of fatty acids, vitamins and other nutrients. The LipiDiDiet clinical trial investigated the effects of Souvenaid on cognition and related measures in the very early stages of Alzheimer’s disease (AD).

Analysis of the first two-year/24-month intervention period showed favourable effects on secondary endpoints of disease progression measuring cognition and hippocampal atrophy. However, the intervention had no significant effect on the primary endpoint (Neuropsychological Test Battery – NTB), which is a combination of widely-used clinical neuropsychological tests measuring memory and executive function.

On 5 November 2020, Tobias Hartmann, Professor of Experimental Neurology at Saarland University (Germany) and coordinator of the European LipiDiDiet project, presented the three-year/36-month results from the European LipiDiDiet study at the 13th Clinical Trials on Alzheimer’s Disease (CTAD) conference. The research results had previously been published in Alzheimer’s & Dementia, the peer-reviewed journal of the Alzheimer’s Association, in September 2020.

Methods

The LipiDiDiet trial was a randomised, controlled, double-blind, parallel-group and multicentre study investigating the effects of Souvenaid on cognition, memory, brain atrophy and related measures in prodromal AD. 311 participants with prodromal AD, aged between 55 and 85 years, received either the nutritional intervention or the placebo in the form of a 125ml once-a-day drink. Participants were spread across 11 study sites in Finland, Germany, Netherlands and Sweden.

36-month results of the trial

A total of 162 participants (85 from the active group and 77 from the control group) completed the 36-month intervention period. Of these 162 participants, data from 81 participants (45 active and 36 control) were eligible for efficacy analysis. Findings showed significant reductions in decline between the intervention and the control group over a treatment period of three years, as measured by the primary (NTB 5-item composite score) and secondary (Clinical Dementia Rating-Sum of Boxes/CDR-SB, memory, hippocampal, ventricular and whole brain atrophy measures) endpoints.

Over 36 months, significant reductions were observed between groups for the NTB 5-item composite score (60% reduction in decline), the CDR-SB (45% less worsening) and the NTB memory domain (76% reduction in decline). In addition, the multinutrient intervention was shown to be safe and well tolerated.

The LipiDiDiet clinical trial showed a significant benefit of Souvenaid over a treatment period of three years, as measured by the majority of the defined primary and secondary endpoints. It slowed decline on clinical and other measures related to cognition, function, brain atrophy, and disease progression. The authors provided evidence that the benefits increased with early and long-term use.

To find out more about the use of Souvenaid in early Alzheimer’s disease, we approached Professor Hartmann, coordinator of the European LipiDiDiet project.
Tobias Hartmann comments

Alzheimer’s disease (AD) research is synonymous with slow progress, but small steps eventually lead us towards achieving bigger goals. Fortasyn Connect did not cure or prevent dementia in the LipiDiDiet clinical trial. Instead, it safely and significantly reduced cognitive and functional decline across the board, notably including the clinically relevant CDR-SB score. One of the lessons learned from all Fortasyn Connect trials is that early treatment makes a difference. This puts mild cognitive impairment (MCI) due to AD very much into the centre of the treatment window for Fortasyn Connect. Keep in mind, however, that compared to the prodromal LipiDiDiet trial, the treatment duration was considerably shorter in the dementia trials, leaving uncharted territory for future research.

When the prodromal LipiDiDiet trial was designed, it was estimated that the first intervention effects would become noticeable after two years. For the full spectrum, and to evaluate the persistence of effects, more time would be needed. After three years, the initial two-year benefits were found to be sustained entirely, and were supplemented by other significant outcomes. Even deceleration of brain atrophy continued. The CDR-SBs Cohen’s d effect size was equivalent to that achieved by established AD dementia drugs, although at a different disease stage. According to the Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) study and similar trials, nutritional intervention can achieve high adherence rates among people with a known or suspected dementia risk. Mirroring this, long-term compliance was high in LipiDiDiet, which is an important factor for the required long-term multinutrient uptake. Over the current total of three years, drop-out and censoring reduced numbers for the main analysis considerably; analysis without censoring pretty much doubled the available data points at the three-year time point and confirmed the results.

From the perspective of therapeutic research, maybe one of the most astounding aspects is that the intervention is a multinutrient. Or perhaps it is not that surprising – after all, ample studies have indicated that inadequate supply of specific nutrients is an early factor in AD. Combining nutrients helped to push things forward one more step and reached what appears to be the current limit of (Cohen’s d) clinical effect sizes observed in AD therapy.

The clinical trials on Fortasyn Connect helped us to gain a clearer picture of what to expect, and of where the limitations are. With these limitations in mind, this multinutrient intervention provides an option for an AD sub-population, where evidence-based choices derived from randomised, controlled and double-blinded clinical intervention trials are very rare.

Future steps might include evaluating potential benefits for at-risk and subjective cognitive impairment or presymptomatic populations. Or aiming to further slow decline by combining this multinutrient intervention with an AD drug or a FINGER multimodal intervention. The FINGER combination might be especially interesting, as this approach already integrates nutrition, plus it originally targeted the at-risk population. With MindAD (a multimodal trial identifying prevention strategies for AD/dementia) and other upcoming trials, research in this area has already begun. It will, however, take years before we know whether any of these factors will boost overall performance, which will sadly be too late for those currently affected.

Acknowledgement

The LipiDiDiet project has received funding from the European Union’s Seventh Framework Programme for research, technological development and demonstration under grant agreement No 211696.
Gina Martin worked at National Geographic for 21 years. She is the Founder and Executive Director of the Bob and Diane Fund, an annual photography award for visual storytelling about Alzheimer’s and dementia.

Ms Martin is the Founder and Executive Director of The Bob and Diane Fund, which offers an annual USD 5,000 grant to photographers whose work tells a story about loss or about the growing health crisis caused by Alzheimer’s and dementia.

The fund awarded its first grant to Swedish photographer Maja Daniels for her project “Into Oblivion”, in 2016. In 2020, it was won by Iranian photographer Jalal Shamsazaran, for his project, “The Loss of Oral History”.

Alzheimer Europe spoke to Gina Martin about the fund, which was named in honour of her beloved parents, and about this year’s winner.

Can you tell us a bit more about the beginnings of the Bob and Diane Fund, and why you created it?

Gina Martin’s mother, Diane, was diagnosed with Alzheimer’s dementia in 2006, which turned her life and that of her family upside down. Bob, Gina’s father, supported and cared for his wife for five years, until she passed away in October 2011. He passed away three short months later.

Can you tell us a bit more about the beginnings of the Bob and Diane Fund, and why you created it?

Alzheimer’s (and dementia) is a disease that, unless you have experienced it, you don’t truly understand it. Working for National Geographic for more than 20 years, I understand the power of visual storytelling. I thought: “Why not combine my two passions (photography and finding a cure for Alzheimer’s) and bring a visual understanding to the disease by supporting photographers and their projects with a wider audience?”

What has been your biggest achievement, so far, with the fund, and what are you most proud of? Has it evolved beyond what you expected?

Oh my gosh, yes, it has evolved! I thought I would just be writing a check once a year and that would be it. In the five years of the fund, I have become much more involved in the Alzheimer’s/dementia community than I ever imagined. I never thought I would speak on the subject or become an advocate – and that has been a pleasant surprise. More importantly, having the honour of so many photographers from around the world knowing about our grant and applying for it. I am amazed each year that we get submissions from 25 different countries – that just blows me away! Then the excitement when the Washington Post publishes the grantees’ work and we get to share the work with the world – which is what we are all about.

What is the thread that connects all the winning projects? What draws you to them in particular?

Hmm, that is a good question. Obviously the one common theme is Alzheimer’s/dementia. Though each one has not necessarily been about a family member, they do each show the disease with honesty and dignity – which is so important. Yes, Alzheimer’s is ugly, sad, and depressing – but there can be a loveliness through caregiving and I do see that in each one. What draws me to each grantee’s project is truly the images and the storytelling. We read every proposal, but we do really look at the images: are they strong? Is the presentation strong? Does it tell a story? Does it tell the story of dementia? In the end, that is what we really look at.
The fund helps to financially support aspiring and upcoming photographers, but what is its wider purpose in the context of the dementia field and community?

We actually support all photographers, from aspiring to professional level. The Alzheimer’s/dementia community is doing amazing work in all aspects from outreach to research. We try to partner and work within this community in bringing the visual awareness to the existing community and to a wider audience.

This year’s winner is Jalal Shamsazaran, for his work on “The Loss of Oral History”. Can you tell us more about the photographer, his project, and why he won?

Jalal applied last year as well and came so close to receiving the grant. He re-applied this year with the same project, but presented differently and it won – deservedly so. In 2018, we chose a black and white project, but not like this one. Jalal’s black and white images
“Obviously the one common theme is Alzheimer’s/dementia. Though each one has not necessarily been about a family member, they do each show the disease with honesty and dignity – which is so important.”

are gritty and journalistic. Every image in his submission was strong. I would not have taken out one of them. That is the experience of a true photojournalist. Washington, DC-based photographer, Jared Soares and I judged the work together and we both were so drawn to his style of photography and his voice throughout. We also liked that fact that he wants to use the grant money to create a book – which takes the work even farther.

How can people apply for the 2021 edition of the award and when is the closing date?

Our grant opens every year in late August/early September. We keep submissions open until the end of October and announce the winner in November, for National Caregivers’ Month.

The photos

All the photos shown in this article are from this year’s winning project, “The Loss of Oral History” by Jalal Shamsazaran. You can view the full project, here: [https://www.bobanddianefund.org/2020-grantee](https://www.bobanddianefund.org/2020-grantee)
Alzheimer Europe hosts its first ever virtual conference

The 30th Alzheimer Europe Conference took place between 20 and 22 October 2020, under the banner “Dementia in a changing world”. In the context of the global pandemic, the event was held online for the first time.

The 30th Alzheimer Europe Conference (#30AEC) “Dementia in a changing world” was formally opened on the afternoon of 20 October 2020. Almost 800 participants from 42 countries attended the event, which was Alzheimer Europe’s first ever virtual conference. On the agenda were 260 speakers and 100 poster presentations, sharing research, projects and experiences in an atmosphere of collaboration and solidarity, against the backdrop of the global COVID-19 pandemic.

Iva Holmerová, Chairperson of Alzheimer Europe, opened the conference, extending a special welcome to the 35 people with dementia who were among the delegates, as well as their supporters. She noted the importance of collaboration in general and highlighted that it is vital to work together, for and with people with dementia, to help them get through this difficult period. Alzheimer Europe and its members continue to work hard to ensure these principals of collaboration and mutual support are upheld.

The pandemic has highlighted many things that are already known, but which are not yet well respected, she said. Modern technologies are becoming more and more necessary, even and especially in older age and for people with dementia. There is also a need to better attune our healthcare systems to vulnerable people and people living with dementia, and to ensure that long-term care workers receive further training to achieve the necessary level of specific skills that are crucial at a time like this. Life brings different risks, one of which is a variety of infections, but, she stressed “it is necessary to go on and live. Be careful, but live.”

Finally, Iva Holmerová reminded delegates of the importance of thinking of our health as part of a bigger picture – as “one health”. We can be healthy only if our planet, our environment, and the animals we live alongside, remain healthy too. We should keep this uppermost in our minds, she concluded.

Following this opening speech, delegates were also welcomed by Helen Rochford-Brennan, outgoing Chairperson of the European Working Group of People with Dementia (EWGPWD) and Myrra Vernooij-Dassen, Chairperson of INTERDEM.

A fond farewell from Helen Rochford-Brennan

Helen Rochford-Brennan addressed delegates from her perspective as a person living with dementia and as the outgoing Chairperson of the EWGPWD. She welcomed everyone to the conference and reflected on how much her life has changed during the pandemic, but also noted that many things remain the same: “People living with dementia continue to have their human rights denied and their voices unheard. We know this pandemic has affected people living with dementia in a disproportionate manner. We are isolated at home, dying in care homes and unable to spend time with family and friends.”

She asked those present to consider what could concretely be done to avoid such a situation happening again in the future, and she implored everyone not to allow the pandemic to stop their important work, particularly in the areas of research and of evidence-based strategies, both for dementia and to put an end to the COVID pandemic.

“I hope this conference motivates you to organise things in your country, find the people living with dementia who are isolated and support them to be involved in research and policy. Become a robust ally. Be someone who asks ‘how can I make it better?’ and then takes action.”

In closing, Helen Rochford-Brennan thanked Alzheimer Europe, The Alzheimer Society of Ireland, her travel supporter Carmel Geoghegan, and her family, without whom the last six years in the EWGPWD (two as Vice-Chairperson and four as Chairperson) would not have been possible. She said that it had been a privilege and a pleasure, expressing particular gratitude to the Board of Alzheimer Europe for accepting a person living with dementia to serve on the Board, and for “sharing power in a meaningful way”, rather than the “all-too-often tokenistic” approach.

INTERDEM calls for a more balanced response to COVID-19

Myrra Vernooij-Dassen spoke on behalf of INTERDEM (Early detection and timely INTERvention in DEmentia). She emphasised that...
social distancing, which is the key measure used to protect against the coronavirus, has had deleterious effects on older individuals and people living with dementia. Measures to protect against the virus were denied to nursing homes and general practices. She emphasised that, during this public health crisis, we need to combat more than just the virus. INTERDEM calls for a more balanced approach, stressing the importance of taking the risk of social, mental, cognitive and physical breakdown into consideration, alongside the risk of infection.

Dementia in a changing world

As part of this year’s new conference format, Alzheimer Europe organised two plenary roundtable sessions, in lieu of keynote lectures. The first of these, “Dementia in a changing world”, saw a panel discussion including Adelina Comas-Herrera, co-lead of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project; Mario Possenti, General Secretary of Federazione Alzheimer Italia; Helen Rochford-Brennan and Lennert Steukers, Associate Director, Janssen Neuroscience Team. This and indeed all plenary sessions at the conference were co-moderated by Jean Georges, Executive Director of Alzheimer Europe and Kim Coppes from Live Online Events.

Panellist Adelina Comas-Herrera, Care Policy and Evaluation Centre, London School of Economics and Political Science, referred to an updated report she co-authored, for which data was collected regarding the impact and mortality of COVID-19 in people living with dementia in nine countries. The percentage of people with dementia in care homes, whose deaths were linked to COVID-19, ranged from 29% to 75% across those countries.

The ban on visits to care homes across the world has kept people with dementia detached from essential affective bonds and from the provision of family care, for many months. There is a pressing need, and also an opportunity for innovation. Guidelines and tools to support institutions and practitioners to respond better to the needs of people with dementia during the pandemic are needed as a matter of urgency, she stressed.

During the discussion, Mario Possenti noted that the work of associations in Italy and beyond may have changed in terms of methods, but not in terms of commitment. “Never before has it been so important to support people with dementia and to commit ourselves to ensure that their rights, health and quality of life are respected”, he said.

Helen Rochford-Brennan focused on how the COVID-19 pandemic has made the need for research and for listening to the voices of people with dementia even more important. She asked her fellow panellists and all delegates to reach out to people living with dementia in their countries and in their local communities; to support them in making sure their voices are heard and listened to; and to ensure they have the opportunity to participate in dementia research.

Lennert Steukers emphasised that a number of stages of research have been impacted during the ongoing pandemic: Discovery/pre-clinical work has suffered due to lab closures and technical unemployment of researchers; clinical work has been hit, with clinical trials being suspended or severely delayed, which may have an impact on data quality; patient involvement has also been difficult due to travel restrictions and only limited face-to-face contact being possible.

The clinical trial landscape has dramatically changed in terms of how these trials are being conducted and will continue to be conducted.
He gave the examples of decentralised, remote and virtual trials, and pointed out some of the challenges this presents in the field of neurodegeneration. There has been a huge impact on the research community, he said, with a whole generation of researchers being affected, for instance due to fellowship schemes/research programmes being stopped.

**Diagnosis and medical management**

The second plenary of the conference was on “Diagnosis and post-diagnostic support” and opened with a presentation on “Improving the diagnosis of neurocognitive disorders: implementing the recommendations of the 2nd European Joint Action on Dementia”, given by Pierre Krolak-Salmon, President of the French Federation of Memory Centres.

We are still facing an under-diagnosis of Alzheimer’s disease and dementia in the field of primary care in Europe, he stressed, noting that the Joint Action recommends new training programmes to help in the fight against the major diagnosis gaps present in primary care. He also shared that a new graduated and personalised diagnosis strategy had been adopted by the Joint Action, which can be adapted to any and all European countries. Finally, he said that advanced practice nurses could help to better detect neurocognitive disorders in primary care.

During the next presentation, on ethical issues linked to the disclosure of diagnosis, clinical neurologist Edo Richard, offered a different perspective, highlighting the impact of a diagnosis and the importance of considering that “timely” diagnosis may not always be synonymous with early diagnosis. The introduction of a biomarker-based diagnosis of Alzheimer’s disease blurs the boundary between health and disease, he said. Finally, he highlighted the widening gap between research and clinical practice around diagnosis of Alzheimer’s disease.

In the third presentation, Simon Lovestone, Vice-President, Disease Area Leader, Neurodegeneration, Janssen, looked at the pharmacological treatment of Alzheimer’s disease and at what we have learned in recent years. Developing therapies for Alzheimer’s disease is particularly challenging for many reasons, he said. The brain is the least understood organ in the body and the disease is inherently complicated, so there are a number of hurdles to overcome when doing clinical trials in this population. He also noted, however, that while clinical trials have not produced a disease-modifying drug, “we have gained tremendous knowledge from years of research and promising efforts are underway that it should only be a matter of time before we see therapies that should delay onset or progression of disease.”

The final presentation was delivered by Gunhild Waldemar, Professor of Neurology and Chairperson of the Danish Dementia Research Centre at Rigshospitalet, University of Copenhagen. She was one of the leading forces in the establishment of the new European Academy of Neurology (EAN) and her presentation, on medical management issues in dementia, shared the new recommendations from the EAN.

She began by pointing out that people with dementia are at increased risk of infections, malnutrition, incontinence, dehydration, adverse effects of certain medications, epileptic seizures, and neuropsychiatric symptoms, and said that medical conditions may go unnoticed in some cases. A lack of treatment, or mis-management of medical conditions may worsen symptoms of dementia, and lead to pain, physical disability, psychiatric symptoms, hospitalisations or even death, she continued. The new EAN guideline, “Medical management issues in dementia”, was
developed by a multidisciplinary working group with the aim of helping to guide physicians on five selected topics: The need for medical follow-up of people with dementia; when and how to treat severe psychiatric symptoms with antipsychotics; the treatment of epilepsy; of vascular risk factors, and of pain.

Building dementia-inclusive societies

The third plenary of the conference explored “Building dementia-inclusive societies”. Dianne Gove, Director for Projects at Alzheimer Europe, opened with a presentation on “Patient and public involvement approaches in dementia research: the experiences and contributions of the European Working Group of People with Dementia” (EWGPWD).

She emphasised that public involvement (PI) is about involving people with dementia throughout the whole research process, as advisors; carrying out research together with people, rather than on or for them. PI provides an opportunity for researchers to learn from people with dementia and the first step in that learning is to render issues and materials accessible to people who have cognitive and other impairments typically associated with dementia. She stressed that “equity is not about simply providing everyone with the same opportunities but about ensuring fairness and equality in outcomes. Reasonable adjustments and adaptations must be made to promote inclusion, in a similar way to the concept of reasonable accommodation in relation to disability.”

Members of the EWGPWD and others like them have a clear desire to have a real impact on dementia research and to influence decision making, whilst also empowering researchers to do good research by sharing with them their unique insight into dementia, she stated. Dianne Gove encouraged researchers and research bodies to “reach out, meet half way, adapt to and learn from each other and from mistakes, respect and value each other’s contribution and make sure that public involvement is not only valuable to research and society but also accessible, rewarding and enjoyable for all involved.”

Sabine Jansen, Executive Director, Deutsche Alzheimer Gesellschaft (DAZG) shared some of the experiences of her organisation, with regards to promoting dementia-inclusive hospitals. She shone a light on how difficult hospital stays can be for people with dementia, stressing that one of the elements that could help to mitigate this would be to involve family carers more in the treatment and care of their loved ones. There are many good practice models which can be used, and although it can be a long road to change structures and approaches for the better, it is possible, she insisted. One of the main barriers, however, is the economic pressure hospitals are under, which prevents them from investing much-needed time into improving infrastructure and care for their patients with dementia.

The third presentation was given by Jacqueline Hoogendam, who is the co-ordinator for dementia policy and international affairs on Long-Term Care at the Ministry of Health, Welfare and Sport in the Netherlands. She listed some of the learnings from the Dutch dementia strategy – the “Deltaplan Dementie” – with regards to making Dutch society more dementia-friendly. First and foremost, she stressed that “persons with dementia matter”, that their wants and needs must be listened to and that they are valuable members of society, who still have abilities, despite some of the negative impacts their condition might have had on their memory, their capacity to carry out certain tasks and to interact with others in the same way they would have previously. One of the focuses of the Dutch National Dementia Strategy 2021–2030 is “Dementia Friendly 2.0: facilitate persons with dementia to use their abilities, to be part of society.”

The final presentation of plenary three was given by John Keady, who leads the inter-disciplinary Dementia and Ageing Research Team at the Division of Nursing, Midwifery and Social Work. He was the Chief Investigator on the multi-site ESRC/NIHR Neighbourhoods and Dementia Study and it was this study and the outcomes of the project which were the main focus of his talk.

He emphasised that neighbourhoods are social spaces as well as physical places, where “mundane” activities take on importance. For
the study, people living with dementia used a range of creative methods and approaches to share their own neighbourhood experiences, as well as helping to develop a Core Outcome Set to communicate what matters most in their everyday lives at home.

From research and innovation to clinical and care practice

The fourth plenary session began with Carol Brayne, Professor of Public Health Medicine and Co-Chairperson of the Cambridge Public Health Interdisciplinary Research Centre in the University of Cambridge, giving a talk on the latest trends in the prevalence of dementia and discussing whether prevention messages are having an effect.

Dementia is changing across generations and within populations, she said. The evidence on prevention clearly points to the fact that primary prevention for dementia risk profiles for whole populations, combined with effective management of existing risk conditions in individuals, is the most effective strategy. On the other hand, she stressed that “there is no evidence that screening and early detection will be effective at present”.

Up next, Alexander Kurz, senior scientist at the Department of Psychiatry, Klinikum rechts der Isar, Technical University of Munich and Director of the university’s memory clinic, shared some of the findings of “INDEED, an interprofessional intervention in dementia education for South-Eastern European countries”. Dementia is a complex disorder that can only be tackled by several health and social care professionals working together, he said. He also stressed that inter-professional shared education is key for collaboration and networking, and can take advantage of modern digital learning formats. The INDEED project provides an online e-learning programme, addressing multiple professions simultaneously and conveys a person-centred, holistic concept of dementia care, he summarised.

In the third presentation, Dympna Casey, Professor and Head of School in the School of Nursing & Midwifery NUI Galway looked at assistive technologies and explored what the role of social robotics could be in dementia.

Carlos Diaz, CEO of Synapse Research Management Partners and Coordinator of the IMI NEURONET project, was the final speaker in plenary four. He discussed the neurodegeneration portfolio of the Innovative Medicines Initiative (IMI), and looked at ways to ensure project results are converted to sustainable assets.

Globally, society is facing several highly complex, urgent challenges, and to be able to respond, he said, scientific research may need a paradigm change in how it is organised. A systems leadership approach is being explored in the IMI neurodegeneration portfolio and it is hoped this will help to propel scientific efforts towards the much-needed actionable results.

Maintaining dementia as a European priority

The fifth and final plenary session took the form of a second roundtable discussion (the first roundtable took place in plenary one, on Tuesday) as part of this year’s interactive virtual conference format. The discussion revolved around “Maintaining dementia as a European priority” and the panellists were Maria Carrillo, Chief Science Officer, Alzheimer’s Association (US) global research program; Dan Chisholm, Programme Manager for Mental Health at the WHO Regional Office for Europe, Nils Dahl, Senior Policy Advisor at Germany’s Federal Ministry of Health; Charles Scerri, Chairperson of the Malta Dementia Society, Vice-Chairperson of Alzheimer Europe and National Focal Point on Dementia in Malta; and Nicoline Tamsma, Policy Officer at the European Commission’s DG for Health and Food Safety, Unit Health Promotion, Disease Prevention, Financial Instruments.

Panellist Maria Carrillo shared the perspective of the Alzheimer’s Association (US) during the conversation, stating that “even now – especially now – Alzheimer’s and all other dementias must be maintained as a global priority. Even during the pandemic, at any given moment, discovery is happening and must not be delayed. As the world’s largest non-profit funder of Alzheimer’s and dementia research, the Association’s commitment to advancing the critical work of the scientific community is unwavering. We are committed to funding researchers
directly, as we also relentlessly pursue additional resources on all fronts, including through our federal advocacy efforts.”

She went on to stress the significant impact that the COVID-19 global pandemic is having on Alzheimer’s and dementia research. That being said, she qualified that some trials – as they are able – are exploring innovative approaches to keep the momentum of their study, and that it is rewarding to see the research community keep this important work going, all the while bearing in mind that “the Alzheimer’s Association’s first priority is the health and safety of study participants and study staff, especially vulnerable elders and people with dementia and their families.” With the COVID-19 pandemic creating multiple challenges for people living with dementia; and with nursing homes, assisted living communities and the families and caregivers of people with dementia all being at the frontline of this crisis; Maria Carrillo also said that the Alzheimer’s Association is working with national, state and local agencies to ensure people living with dementia have access to high quality, person-centred care.

During the discussion, Dan Chisholm emphasised that dementia represents a public health challenge of international concern, especially in the context of rapidly ageing populations and drew attention to the fact that COVID-19 has served to expose the shortcomings of most countries’ preparedness and response capabilities, not only with respect to viral disease outbreaks but also to healthy ageing, dementia and long-term care.

“The WHO continues to work through the crisis with its Member States and partners to develop and make available tools and other measures to support implementation of its global action plan on the public health response to dementia, including a dementia-friendly and inclusion toolkit as well as risk-reduction guidelines for cognitive decline and dementia”, he said, and he pointed out that the WHO has also rapidly stepped up its work to provide guidance to countries on COVID-19, including clinical management, psychosocial support needs and maintenance of essential care and services.

Nils Dahl assured delegates that, during the past decade, Germany’s Federal Government has initiated numerous programmes and measures to support people with dementia and their relatives, culminating in the development of the country’s national dementia strategy and its adoption by the Federal Cabinet in July 2020. Amid the pandemic, the implementation of the dementia strategy remains a priority for the government, he stressed. He also emphasised that all actors involved in the process of the strategy’s implementation would take into account that persons with dementia might not only be at high risk of falling seriously ill if infected with COVID-19, but that they can be adversely affected by COVID-19-related restrictions as well.

Speaking about the current pandemic and its impact on people with dementia and carers, Charles Scerri stated that “times like these have taught us the importance of coming together, as European nations, in supporting individuals living with dementia” and that this could be achieved through innovative resources directed towards maintaining their wellbeing. We have also learned that individuals living with dementia, and those who care for them can become particularly vulnerable during such a crisis, he continued, insisting...
that “Europe must do more by investing in more research, putting dementia as a top priority in its health and social programmes.”

Nicoline Tamsma drew attention to some of the Commission’s efforts to see dementia recognised as a priority, such as supporting initiatives via the EU Health Programme, including two Joint Actions, the second of which helped advance work on diagnosis and post-diagnostic support, crisis and care coordination, residential care, and dementia-friendly communities. Since 2014, via Horizon-2020, EU funds targeted to brain research totalled EUR 3.17 billion, which included EUR 683 million for research into neurodegenerative diseases, the majority of which, she noted, had been dedicated to Alzheimer’s disease and dementia. The Commission also continues to support the work of Alzheimer Europe.

With regards to how the pandemic has affected progress in the area of dementia research, the Commission is working with Member States and international partners to tackle COVID and its consequences, she said. Together with WHO Europe and the European Observatory on Health Systems and Policies, the Commission monitors how national health systems respond to the pandemic, including a focus on measures taken to protect care homes.

Addressing the mental health impact, she pointed to a specific network space on the EU Health Policy Platform, set up by the Commission to support stakeholders and to facilitate practice and knowledge exchange, also with regard to vulnerable groups such as people with pre-existing conditions. Alzheimer Europe is among more than 65 participants.

Answering the question, “how can we ensure that dementia remains a priority at national, European and global level and what should priority actions be?”, Nicoline Tamsma highlighted the Commission’s mandate in the field of public health centres on providing support to Member States and shared that DG SANTÉ had set up a mechanism to identify and implement good practices and implementable research results. Through the Steering Group on Health Promotion, Disease Prevention and Management of NCDs, Member States select priorities and practices of most relevance to them and the Commission then supports their implementation through EU financial instruments, such as the Health Programme.

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), Roche, Biogen, the European Federation of Pharmaceutical Industries and Associations (EFPIA) and BBDiag.

All delegates were invited to mark the dates of the next Alzheimer Europe Conference (#31AEC) in their calendars. “Building bridges” will take place in Bucharest, Romania from 29 November to 1 December 2021.
Six special symposia held during #30AEC

On 20, 21 and 22 October 2020, during the 30th Alzheimer Europe Conference (#30AEC), six special symposia were held.

European Working Group of People with Dementia (EWGPWD): “My second new life: adapting after COVID-19”

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). Members of the group shared individual videos, in which they talked about how the pandemic has affected them personally, and how they have managed to adapt to new circumstances and a “new life”.

The members of the group who shared videos were: Idalina Aguiar (Portugal), Nina Baláčková (Czech Republic), Stefan Eriksson (Sweden), Tomaz Gržinič (Slovenia), Carol Hargreaves (United Kingdom – Scotland), Bernd Heise (Germany), Angela Pototschnigg (Austria), Helen Rochford-Brennan (Ireland) and Geert Van Laer (Belgium).

The group hopes that these video clips will inspire people with and without dementia and give them hope that it is possible to find new ways to adapt during this pandemic, and beyond.

The videos are available to view on our YouTube channel.

Lessons from COVID-19 for AD health system readiness

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

This special symposium, sponsored by Roche, brought together an expert panel to share their perspectives on and experiences of the lessons to be learned from COVID-19 for AD health system readiness, and to explore a range of topics, from healthcare access and service coverage, to capacity constraints, the respective roles of primary and specialist care, and how to ensure medical innovation can support a patient-centred care model in AD.

Dementia care and COVID-19

This special symposium brought together four speakers to discuss the impact of the pandemic on people living with dementia and specifically on their access to care, from the perspectives of: a research institution (Fundació ACE); two national Alzheimer associations (Alzheimer Scotland and The Alzheimer Society of Ireland); and migrant family carers.

Mercè Boada detailed the sequence of events and actions undertaken within the Fundació ACE Memory Clinic to swiftly adapt to telemedicine consultations. She shared data on individuals under follow-up by the Memory Unit between 2017 and 2019, comparing this data with the number of weekly visits in 2020, before and after lockdown. Videoconference visits have become the norm, and neurologist and neuropsychologist evaluation protocols have rapidly been adapted to the new situation.

Carolien Smits (Pharos, Netherlands) shared that the COVID-19 era and ensuing government measures have resulted in anxiety and
Increased burden for migrant family carers. Professional care quality is under pressure and is becoming less culturally sensitive, in some cases.

Nicola Cooper presented the experience of Alzheimer Scotland which, in a few short weeks, transformed its care approaches through the use of technology, experiencing a paradigm shift in how it delivers services. Over 200 staff undertook digital skills training and now use the NHS approved Attend Anywhere video platform to deliver 131 support and a range of therapeutic group activities, including cafes and ceilidhs, for service users at home and in care settings.

Bernadette Rock (The Alzheimer Society of Ireland) In turn discussed Ireland’s experience of emergency psychosocial supports for people with dementia and their families. The outbreak of COVID-19 forced the closure of almost all community-based dementia-specific services and supports in Ireland, leaving thousands of people with dementia and family carers to fend for themselves. Specific needs of people with dementia, family carers and other stakeholders were identified via online and telephone surveys and, using this data, The Alzheimer Society of Ireland developed a new suite of emergency supports and services.

It is time for European healthcare systems to prepare for Alzheimer’s breakthroughs?

Currently, health systems in Europe are not ready to get the most out of potential breakthroughs in disease modifying therapies for Alzheimer’s disease and other dementias. To be able to fully benefit from these therapies, complex health systems will have to adapt and change and will have to ensure that they can detect and diagnose dementia early, deliver new medicines by infusion, and monitor treatment. While most of these improvements will need to be undertaken locally, by national and regional governments, there are also significant steps that can be taken at the European level.

The panel discussion in this symposium, which was organised by The European Federation of Pharmaceutical Industries and Associations (EFPIA), was an opportunity to raise awareness about the need for European healthcare systems to plan for Alzheimer’s breakthroughs and to identify solutions. “The time for action is now”, was the overriding message.

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

Over the course of the last decade, research into the pathophysiology of Alzheimer’s disease has shown that early intervention will be important to maximise outcomes for the patient. Currently, detection, diagnosis and care planning all start once symptoms start to become more apparent, which is very often late in the disease course. To benefit from future advances in treatment and care, healthcare systems will need to appropriately recognise, diagnose and support people at the earliest stages of the disease – perhaps even before symptoms appear. Creating a policy response to drive the healthcare system to meet the emerging science will require support at both the regional and country levels to take urgent action.

In a time of social distancing and uncertainty in the world of healthcare, collaboration and communication among all stakeholders is more important than ever. This symposium sponsored by Biogen, offered perspectives from a variety of stakeholders, to better understand the current state of treatment and care, and where challenges exist in the patient journey. Participants examined ways in which healthcare systems are improving detection and diagnosis and reviewed policy actions to address barriers to challenges, such as late stage or misdiagnosis.

Medical management of dementia

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

The sixth and final symposium at the virtual Alzheimer Europe Conference explored the guideline of the European Academy of Neurology on “Medical management issues in dementia”. The Guideline aims to support physicians on a number of important medical management issues in the care of patients with dementia, including: systematic medical follow-up; treatment of vascular risk factors; management of pain; treatment of agitation and aggression with anti-psychotics, and management of epilepsy.

Four of the authors of the Guideline were present to answer questions.

Showcasing European research initiatives at #30AEC

Neuronet – A coordination and support action bringing together 18 IMI consortium projects working on neurodegenerative disease and the Horizon 2020-funded VirtualBrainCloud (TVB_Cloud) project were strongly represented at the 30th Alzheimer Europe Conference (#30AEC).

Neuronet

Neuronet has been designed to boost synergy and collaboration across the projects of the Innovative Medicines Initiative (IMI) Neurodegenerative Disorders (ND) portfolio. With a total funding budget of EUR 386 million, and addressing the whole R&D spectrum from preclinical science to real-world data, the IMI ND portfolio brings together 18 consortium projects and over 230 partnering organisations.

Since its launch in 2019, Neuronet’s support activities have focused on key areas identified by projects as challenging, including data sharing and accessibility, working with regulators, and ensuring patient privacy. The Neuronet parallel sessions held as part of the conference were designed to showcase the work of IMI ND projects in these key areas, stimulating discussion on major issues and how to address them.

The first session, chaired by Carlos Díaz (SYNAPSE Research Management Partners), was entitled “Efficient data sharing: a must for science to respond to societal needs”. During this session, Nigel Hughes, Rodrigo Barnes and Colin Veal from the EHDEN and EPAD IMI projects discussed technical solutions that are being developed by IMI projects to overcome key obstacles to effective sharing of health data, including data harmonisation, federated networks, digital data discovery tools and research environments.

The second Neuronet session, entitled “Ensuring ethics and patient privacy whilst boosting research”, was chaired by our very own Jean Georges and included presentations from Nathan Lea, Pilar Cañabate and Sébastien Libert of the EMIF, MOPEAD and RADAR-AD projects, showcasing how they have addressed ethical and legal concerns around the use of remote monitoring technologies, autonomy and information governance for big data research. The next topic to be addressed was Regulatory & HTA assessment, in a session chaired by Diana O’Rourke of NICE. Presentations from Gill Farrar, Jacoline Bouvy and Marco Viceconti illustrated how the AMYPAD, ROADMAP and Mobilise-D IMI projects are actively engaging with European regulators, to identify pathways for approval of neuroimaging and digital biomarkers.

Neuronet project leader, Lennert Steukers closed off the 2020 Neuronet sessions, moderating a discussion on how COVID-19 has affected large public-private partnership projects. In this roundtable session, IMI project leaders who are experts on mobility disorders, digital biomarkers, stratified medicine and dementia prevention discussed the research challenges caused by the ongoing pandemic, and how to ensure that neurodegenerative disease research remains a priority in the post-COVID period.

VirtualBrainCloud

Elsewhere at #30AEC, the Horizon 2020-funded VirtualBrainCloud (TVB_Cloud) project held two sessions on the use of artificial intelligence (AI) in dementia research. In the first session, chaired by Katarina Stevanovic of TP21, project leader Petra Ritter (Charité Medical University Berlin) presented the TVB_Cloud approach to develop a cloud-based platform for personalised diagnosis and treatment of dementia.

Martin Hofmann-Apitius of Fraunhofer SCII outlined their knowledge graph approach to increase our mechanistic understanding of neurodegenerative disease, and to identify potentially druggable pathways. Viktor Jirsa (Aix-Marseille University) rounded off the session, illustrating how algorithms developed to analyse complex systems could help us understand brain networks in health and in disease.

The second TVB_Cloud session addressed the ethical, legal and social issues raised by the use of AI in dementia research. Bernd Stahl, Ethics Director of the Human Brain Project, outlined how some of the ethical issues raised by the use of AI in healthcare research could be mitigated at policy, organisational and project levels, to ensure that the benefits of AI do not outweigh the risks. Data protection is a major concern for big data research using AI, and Michael Cepic (University of Vienna) guided the audience through the General Data Protection Regulation, showing...
how it protects patient privacy whilst enabling health and care research.

Rounding off the session, Richard Milne of the Wellcome Sanger Centre addressed the benefits and harms of risk disclosure when risk is detected using algorithm-based approaches, describing a potential route to mitigate harms whilst maximising benefit.

Acknowledgements

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The VirtualBrainCloud project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 826421.

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).
#30AEC – A highly interactive conference

Our first ever 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.
Are there innovations we should keep after the pandemic is over?

- Remote counselling and support: 76%
- Family visits via teleconferencing: 61%
- Online diagnostic screening and referral: 34%
- Online recruiting for research projects: 42%
- We should return to the pre-pandemic situation: 14%

On a scale of 1 (very badly) to 10 (very well), how would you rate the #30AEC conference?

8.89

If you were here yesterday, describe in a word what you learned/experienced?

7.18

How did you sleep last night? (from 1=very badly to 10=very well)

7.18

Dementia in Europe
Facts and figures

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</tr>
<tr>
<td>Israel</td>
<td>1</td>
</tr>
<tr>
<td><strong>Grand Total</strong></td>
<td><strong>756</strong></td>
</tr>
</tbody>
</table>

- **Academic or researcher**: 302
- **Alzheimer association staff or volunteer**: 164
- **Health or social care professional**: 105
- **Industry representative**: 66
- **Student**: 48
- **Person with dementia**: 36
- **Policy maker**: 15
- **Civil Servant**: 11
- **Family carer**: 8
- **Press**: 1

**99.04%** of delegates would recommend future Alzheimer Europe Conferences to their colleagues.

**96.23%** of delegates rated the opening ceremony, plenaries and closing ceremony of the conference to be good/very good.
Our members are helping people with dementia and their carers in 35 countries.
31st Alzheimer Europe Conference
Building bridges
Bucharest, Romania
29 November to 1 December 2021

www.alzheimer-europe.org/conferences    #31AEC