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Minister for Family Affairs, Senior Citizens, Women and Sport discusses the new German National Dementia Strategy

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Vice-Chairperson: Charles Scerri (Malta)
Honorary Secretary: Jim Pearson (UK – Scotland)
Honorary Treasurer: Marco Blom (Netherlands)

Members
Chris Roberts, Chairperson of the European Working Group of People with Dementia
(UK – England and Wales)
Stefanie Becker (Switzerland)
René Friederici (Luxembourg)
Sabine Jansen (Germany)
Pat McLoughlin (Ireland)
Sirpa Pietikäinen (Finland)
Karin Westerlund (Sweden)
Maria do Rosário Zincke dos Reis (Portugal)

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Christophe Bintener, Project Communications Officer
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Kate Boor Ellis, Communications Officer
Angela Bradshaw, Project Officer
Ana Diaz, Project Officer
Dianne Gove, Director for Projects
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Owen Miller, Policy Officer
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Welcome

I am delighted to introduce the 34th edition of Dementia in Europe – the Alzheimer Europe magazine. Following the success of the previous edition in a digital-only format, we have decided to continue in a digital-only format for this edition. I hope you enjoy the magazine and the many interesting stories and developments within!

The first section of the magazine examines recent developments in relation to Alzheimer Europe and its work, which have continued despite the ongoing pandemic. We begin by welcoming the newly elected members of the Alzheimer Europe Board who will serve until 2022. We also bid a fond farewell to Helen Rochford-Brennan with an interview piece about her time in the group and in the role of Chairperson, which she held from 2016–2020. Our next article gives some background about and details of our recent position statement on the impact COVID-19 is having on dementia research.

In the area of research, we focus on three of the European projects in which we are currently involved: We share some details of the PARADIGM project’s ongoing Patient Engagement Open Forum which is held as a series of online events; we examine developments in the RADAR-AD project, including the involvement of some members of the EWGPWD in the project’s Patient Advisory Board; and finally, we take a look at the findings from the now-concluded MOPEAD project.

In the Policy Watch section, we are delighted to feature an interview with the European Commission’s Vice-President for Democracy and Demography, Dubravka Šuica, in which she outlines the EU’s forthcoming Green Paper on Ageing and where dementia fits into this work. In the next article, we were pleased to speak with the German Minister for Family Affairs, Senior Citizens, Women and Youth, Franziska Giffey, who shared details of the new German National Dementia Strategy. In this section we also have details of the European Group of Government Experts on Dementia, which met online in June to discuss policy developments from across Europe. We then outline the latest EU policy developments in relation to the long-term budget of the EU, as well as health and research policies. Then Stéfanie Fréel and Katrin Seeher of the World Health Organization (WHO) share progress on key areas of work, such as the new knowledge exchange platform as part of the Global Dementia Observatory (GDO) and a new toolkit for dementia inclusive initiatives. Rounding off the policy developments, we provide an update on COVID-19 exit strategies across Europe, in relation to people with dementia and their caregivers.

In the third section, Dementia in Society, we open with an interview with Kate Lee, the new CEO of the UK Alzheimer’s Society. She discusses her vision for the future of the organisation and their next steps. A new working group of people with dementia launched in Vienna, Austria, in the early part of this year. The group, “Turn the Corner”, had to put some of its planned meetings and activities on hold during confinement, but has since been able to kick-start them properly. We hear from Angela Pototschnigg, a member of both the EWGPWD and Turn the Corner, about the group’s aims and hopes. This section also features a commentary piece with Professor Gill Livingston, the lead author of “Dementia prevention, intervention, and care: 2020 report of the Lancet Commission” who outlines how best to try and prevent dementia and support those living with the condition. Four other experts in the field also provide their comments, giving us the European research project perspective (EU-FINGERS, PRIME, RECOGNISED and ADAIR).

We are grateful to Claire Days of the LGBT Foundation and to campaigner Patrick Ettenes for their article about the Bring Dementia Out campaign in the UK. The campaign seeks to challenge the stigma faced by LGBT+ persons with dementia, taking a rights-based approach. Finally, in this section, we hear from Anna Borthwick, Executive Lead of the newly-launched Brain Health Scotland initiative. Brain Health Scotland, developed in partnership with Alzheimer Scotland and funded by the Scottish Government, aims to help people of all ages to protect their brain health and reduce their risk of developing diseases including dementia.

We have a special section to round off this edition of the magazine! This year marks the 30th anniversary of Alzheimer Europe and we open with an interview with Executive Director, Jean Georges, who reflects on his 24 years with the organisation and his views on the many achievements during this time. In the next article, I share my thoughts on the key areas of work for the organisation and the role of the Board as Alzheimer Europe has evolved and grown over the years. Outgoing Honorary Treasurer, Maria do Rosário Zincke dos Reis then provides her insights on the financial position of the organisation and how this has changed over time. The final article looks back at some of the key milestones in Alzheimer Europe’s 30 years leading the European Dementia Movement, marking the evolution of the organisation’s work over time. Much has been done in these 30 years and there is much still to do!

I wish you all continued good health in these challenging times!
Alzheimer Europe elects new Board

On 5 October 2020, Alzheimer Europe held its Annual General Meeting (AGM) online. Member associations elected the Board of Directors which will now serve until October 2022.

Alzheimer Europe’s Board of Directors is comprised of the office bearers – Chairperson, Vice-Chairperson, Honorary Secretary and Honorary Treasurer – and up to seven further members directly elected by a General Meeting. The Chairperson of the European Working Group of People with Dementia (EWGPWD) is an ex-officio member of the Board of Directors with full voting rights. All directors must be members of full member organisations of Alzheimer Europe.

Iva Holmerová (Czech Republic) – Chairperson

Iva is a founding member and former Chairperson of the Czech Alzheimer Society. She holds a PhD in Social Gerontology and is a practicing physician in General and Geriatric Medicine. Iva is also the Director of the Czech Centre of Gerontology, President of the Czech Society of Gerontology and Geriatrics, and committee member of the International Association of Gerontology and Geriatrics. She is an Associate Professor of Humanities at Charles University (Prague) and was named Visiting Professor at the University of the West of Scotland in 2014. Iva joined the Board of Alzheimer Europe in 2008, serving as Vice-Chairperson from 2010–2016 and has been Chairperson since 2016.

Charles Scerri (Malta) – Vice-Chairperson

Charles holds a PhD from the University of Dundee, Scotland. He lectures in dementia studies at the University of Malta and is the National Focal Point on Dementia in Malta. He is also the Chairperson of the Malta Dementia Society and a member of the European Union Joint Programme for Neurodegenerative Diseases (JPND) Scientific Advisory Board and Early Detection and Timely Intervention in Dementia Group (INTERDEM). Charles has been Vice-Chair of Alzheimer Europe since October 2016. Prior to this, he was Alzheimer Europe’s Honorary Secretary.

Jim Pearson (UK – Scotland) – Honorary Secretary

Jim is Alzheimer Scotland’s Director of Policy & Research, responsible for Alzheimer Scotland’s public policy engagement. He is also responsible for research engagement. He has a background in welfare rights and a particular interest in promoting as well as protecting the rights of people living with dementia. He played a significant role in developing Scotland’s Charter of Rights for people with dementia and their carers, which puts human and other legal rights at the heart of each commitment of Scotland’s first and second dementia strategies. He joined the Board in 2014 and took the position of Honorary Secretary in October 2018.

Marco Blom (Netherlands) – Honorary Treasurer

Marco graduated from Radboud University Nijmegen in 1987 with an MSc in Psychogerontology. After working in a regional mental health institute for elderly people and at the National Institute of Care and Welfare, he joined Alzheimer Nederland in 1997. He has held several different positions, including interim CEO (2017–2018). Currently, he is scientific director and also head of National Services. Marco is also a Board member of the national Delta Plan Dementia in the Netherlands and editor of Denkbeeld – a Dutch journal on dementia care. He joined the Alzheimer Europe Board in October 2018 and took the position of Honorary Treasurer in October 2020.

Chris Roberts (UK – England, Northern Ireland and Wales) – Chair of the EWGPWD

Chris was the Vice-Chairperson of the EWGPWD from 2016–2020 and has been confirmed as the new Chairperson, thus also joining the Board of Alzheimer Europe. He is from Wales and was diagnosed with mixed dementia (Alzheimer’s and vascular) in 2012. He is passionate about advocating for people living with dementia, their rights, inclusion, and for better services for everyone living with dementia. He has an Honorary Fellowship at Bangor University and is a member of the Dementia Oversight of Implementation and Impact Group, helping monitor progress made on Wales’ national dementia plan.

Stefanie Becker (Switzerland)

Stefanie is the Director of Alzheimer Switzerland and is a trained psychologist and gerontologist, with a PhD in Psychology from Karl-Ruprechts University of Heidelberg. She has worked for the German Centre for Research on Ageing, the research group of Psychogeriatrics at the Centre of Mental Health in Mannheim, and at the University of Applied Sciences in Bern as Director of the Institute of Aging. She also held the presidency of the Swiss Society of Gerontology and Geriatrics from 2012–2016. She is a member of the strategic board of the Swiss National Dementia Platform and of several workings groups of the Federal Office of Public Health. Stefanie joined the Alzheimer Europe Board in 2016.
René Friederici (Luxembourg)

Since 2015, René has served on both the Board and the Executive Board of Association Luxembourg Alzheimer. He previously worked for 25 years in an international engineering & project management company, where he latterly held the position of Senior Vice-President responsible for the human resources management of 1,500 people in 20 countries across the globe. He is also an Officer of Rotary International and has held a number of club functions over the past 25 years. In 2018–2019 he was nominated District Governor for Belgium and Luxembourg, coordinating 92 Rotary Clubs. He joined the Board of Directors of Alzheimer Europe in October 2020.

Sabine Jansen (Germany)

Sabine is the Executive Director of the German Alzheimer’s association, Deutsche Alzheimer Gesellschaft (DAIzG), an umbrella organisation of more than 130 regional and local Alzheimer associations. Before joining DAIzG at its Berlin chapter in 1995, Sabine completed her studies in social work and worked in various fields of the health sector. She is a member of a number of advisory boards, including the Ministry of Health and various research projects. She is working closely with German ministries to help implement the new National Dementia Strategy in Germany, Sabine joined the Board of Alzheimer Europe in 2016.

Pat McLoughlin (Ireland)

Pat worked in consultancy prior to becoming Chief Executive Officer of The Alzheimer Society of Ireland (ASI) in 2016, where he actively participates in lobbying and national campaigns for the rights of people with dementia and carers. Under his leadership, the ASI has been successful in having its campaign issues reflected in the current Irish government’s “Programme for Government”. Pat was previously CEO of two Health Authorities, Deputy CEO of the Irish Health Service Executive and Director of public hospitals. He was also CEO of Ireland’s Payments Clearing System. He joined the Board in 2018.

Sirpa Pietikäinen (Finland)

Sirpa Pietikäinen MEP, former Finnish Minister of the Environment (1991–1995), has been a Member of the European Parliament since 2008. At the Parliament, she is currently a member of the Economic and Monetary Affairs Committee, and the Women’s Rights and Gender Equality Committee, as well as a substitute member of the Environment, Public Health and Food Safety Committee. She has a keen interest in the area of health and dementia, working with various organisations, including as Vice-President of the Union Council of the Alzheimer Society of Finland, since 2013, and the Alzheimer Europe Board, since 2010.

Karin Westerlund (Sweden)

Karin holds an Executive MBA from Stockholm School of Economics and a Bachelor Degree in financial economics from Stockholm University. Her work for Alzheimer Sweden started in 2015, with a 3-year inquiry about persons with Alzheimer’s disease and Down’s Syndrome. She then began her work as a Consultant and Investigator for the organisation, focussing on dialogue with the relevant Swedish Public authorities. She joined the Board of Alzheimer Europe in 2018.

Maria do Rosário Zincke dos Reis (Portugal)

Rosário has been practicing law in Portugal since 1987, focussing on family law and the legal rights of people with diminished capacity. She joined the Alzheimer Europe Board in 2008, and became Honorary Treasurer in 2010, a role which she held for 10 years, handing over to Marco Blom in October 2020. She was the Chairperson of Alzheimer Portugal from 2000–2012, a member of the Audit Committee of Alzheimer Portugal from 2012–2016 and is a current Alzheimer Portugal Board member. Rosario is also a trainer on Legal and Fundamental Rights of elderly people and people with incapacity and is a member of the Portugal’s National Ethics Committee of Clinical Research, (CEIC).

Farewell to a departing Board member

Alzheimer Europe wishes to thank outgoing Board member Jesús Rodrigo for his service and we look forward to our continuing work alongside him and his organisation, CEFA.

First ever online AGM for Alzheimer Europe

In view of the ongoing pandemic, Alzheimer Europe held its AGM as a virtual meeting this year, for the first time ever. The meeting took place on 5 October and 28 out of 35 full member organisations were in attendance or represented.

Jean Georges, Executive Director shared some of the organisation’s achievements in 2019 and 2020. In addition, Jim Pearson, Honorary Secretary, introduced the Annual Report 2019, whilst Maria do Rosário Zincke dos Reis, Honorary Treasurer, presented Alzheimer Europe’s finances for 2019–2020. Plans for 2021 were also shared with delegates, as were the finances of the organisation and a number of relevant developments in the EU. Matters related to membership fees for the coming year were also discussed and agreed upon.

Highlights of the meeting included the Board elections, welcoming Social Cluster Association (Hungary) as a full member of Alzheimer Europe, and an address given by Helen Rochford-Brennan, outgoing Chairperson of the European Working Group of People with Dementia (EWPWP).
Helen Rochford-Brennan reflects on her time as Chairperson of the European Working Group of People with Dementia

In October 2020, Helen Rochford-Brennan said goodbye to her colleagues in the European Working Group of People with Dementia (EWGPWD) after six years in the group; four of these in the role of Chairperson. She spoke to us about her time with the group and the achievements she is most proud of.

You joined the European Working Group of People with Dementia (EWGPWD) in 2014. What were your reasons for joining and what were your expectations? Were these expectations met?

I joined the group because I believed it was an opportunity to influence policy at a European level. I saw a real opportunity to change policy through the parliament and my professional background advocating for the rights of people with disabilities gave me the confidence to join the group. I wanted to work to make the lives of people living with dementia and their families better and in particular to be a voice for people living in rural areas. There are many spokes on the wheel of life but first we’re here to explore new opportunities and that’s why I was so driven to join a group I felt could make real change.

I expected the EWGPWD to be serious and solemn. I was very apprehensive about language and wondered how this would work! I wasn’t expecting the strong voices of advocacy that I encountered, and at my first meeting I saw their need for change was like mine! I definitely was not expecting the sense of fun and camaraderie either. This experience has been one of the privileges of my life.

Once I saw that Alzheimer Europe was willing to listen and take on board the views of the EWGPWD, I knew we could influence real change. We did not just talk, our conversations led to action.

You served as Vice-Chairperson from 2014 to 2016 and then became Chairperson of the group in 2016. What did it mean to you to hold these positions and could you share one or two personal highlights from the past six years?

There have been many achievements and highlights over the years. On a personal level accepting the Mano Amiga award on behalf of the group was a wonderful moment, as was attending the European Parliament. Seeing MEPs listen and engage with people living with dementia was very special. Standing beside three MEPs from my home country and knowing their commitment to the cause gave me great hope. Being invited to the European Parliament Disability Forum and watching my colleague Chris Roberts speak at that event made me very hopeful for the future.

But the real highlight has been watching my colleagues in the EWGPWD build their capacity, grow in confidence and influence change in their own countries. I feel very proud to be part of this group of change makers.

What do you think has been the EWGPWD’s biggest achievement so far and what do you hope it can achieve in the future?

The EWGPWD is now an important stakeholder in the European dementia landscape and this is an important and critical achievement in the human rights of people with dementia.

I believe that the EWGPWD, supported by Alzheimer Europe, has been part of a Europe-wide shift in the mind-set of researchers. Now, funding requires researchers to include the voice of people living with dementia; they are now co-creators and robust partners. I think the leadership shown by members of the EWGPWD will influence research and policy for years to come.
The group was originally formed to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia, and more recently, to contribute towards research projects in the context of Public Involvement. Do you think these goals have been achieved?

Yes I do. I believe the engagement has been meaningful and not tokenistic. Alzheimer Europe has approached this work in a very ethical manner. It was a great honour to sit on the Board of Alzheimer Europe and I believe this is an important example of shared power and how the voice of people with dementia can influence at the highest level.

Of course it is a work in progress, and there is more work ahead – that’s a reminder for my colleagues coming after me: no slacking!!

The achievements of these recent years have been considerable.

What are some of the main obstacles encountered in the important work the group does?

The main obstacle has been the language barrier. More people from many different countries could participate if there was funding for interpreters. We must be careful, going forward, that we are finding and listening to the voice of the person with dementia and not their support person, if there is a language difficulty.

As such a passionate advocate for the rights of people living with dementia, what are your plans for further work in this area?

I will never give up fighting for the rights of people with dementia, while I still can. I remain a member of the Irish Dementia Working Group and I am on the monitoring committee of the National Dementia Strategy in Ireland. Indeed, they had better watch out, because I have more time now!

I am very involved, too, with the National University of Ireland Galway and the work of the Global Brain Health Institute (GBHI) Fellows. I am passionate about research and I really enjoy supporting researchers.

Spending time with my family and my new dog Lexie is also in my plans, as is enjoying my garden! I feel very lucky to have such a loving family and a supportive community, and although I will miss my European work I am ready for this new chapter.

I want to thank the teams at Alzheimer Europe and The Alzheimer Society of Ireland, I have gotten the most tremendous support. Without their commitment the EWGPWD could not achieve what we have achieved.

Mile Buiochas!

Attending the European Parliament was one of my personal highlights. Seeing MEPs listen and engage with people living with dementia was very special and standing beside three MEPs from my home country, knowing their commitment to the cause gave me great hope.”

On 22 October 2020, following the 30th Alzheimer Europe Conference, the European Working Group of People with Dementia (EWGPWD) begins a new two-year term. Chris Roberts was confirmed as the Chairperson for this new term, at a meeting of the EWGPWD in June 2020. Chris was the Vice-Chairperson of the group, from 2016–2020. Alzheimer Europe will publish an article in its Dementia in Europe magazine in February 2021, introducing the new group.
Alzheimer Europe calls for urgent action to address COVID-19 impact on research

Following engagement with its national members, research funders and industry partners, Alzheimer Europe issued a position statement on 28 July 2020, highlighting the pressure on dementia research as a result of COVID-19 and setting out a number of recommendations on how they should be addressed.

Background

As a result of the COVID-19 pandemic, disruption has been caused to all aspects of life across the world, as measures aimed at slowing the spread of the virus (social distancing, lockdown, closing of places of work etc.) have interrupted normal ways of working. As Alzheimer Europe engaged with its membership, research funders and industry partners throughout the course of its work, it became apparent the extent to which this was also true for researchers working in laboratory and clinical settings. A multitude of overlapping issues (furloughing or redeployment of staff, closure of services etc.) have resulted in research and projects being put on hold.

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

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

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

The need for greater support and flexibility for existing dementia research projects

Addressing the issues faced by existing dementia research projects affected by the pandemic, the position statement calls for:

- Research funders to show the maximum possible flexibility for funding recipients, to ensure resources can be allocated as required to allow for the completion of projects
- Research funders to work with recipients to ensure that existing data, findings and outputs from projects are collated
- Research organisations to offer flexibility and accommodation to researchers (especially early-career researchers), taking steps to provide opportunities and further development to ensure their continued career progression
- The EU and national governments, through economic responses to COVID-19 (e.g. the EU Recovery Instrument), to support research institutions and researchers to ensure they do not lose out financially.

The impact on dementia research funding streams as a result of COVID-19

In addition, the position statement noted that many funding streams for dementia research have been halted or redirected, therefore it calls for:

- National research funders to resume, as early as is practicable, calls for dementia research
- The EU and national governments, through economic responses to COVID-19 (e.g. the EU Recovery Instrument), to ensure that research funding is not significantly diminished as a result of the pandemic.

The need to prioritise dementia in post-pandemic future research

Looking towards a post-COVID-19 landscape, the position paper highlights long-standing disparities in funding for dementia research, noting that this has been exacerbated by the pandemic, calling for:

- National research funders and governments to provide increased funding and resources for dementia research, in line with other conditions (e.g. other non-communicable diseases) and reflecting the aims of the 2013 G8 Communiqué
- National research funders, institutions and researchers should look explore the possibilities of adopting new ways of working, such as online and virtual platforms, where suitable, to allow research to continue even where physical distancing restrictions may continue, including the ethics of these new approaches
- The EU to include a dedicated strand of work dedicated to dementia research within the Horizon Europe research programme (2021–2027)
- National research funders should adopt an approach focused on prevention, care and cure, spanning the whole range of dementia research from basic to care research
- Governments and research funders to give specific attention to the psycho-social aspects of dementia when assessing and considering the vulnerability of persons with dementia and their carers, including in relation to the impact of COVID-19.
PARADIGM project organises online Patient Engagement Open Forum

The PARADIGM project’s Patient Engagement Open Forum was organised online this year, due to the ongoing COVID pandemic. It was decided to have a series of online events, running from June to November 2020.

The Patient Engagement Open Forum (PEOF) is an event which aims to explore patient engagement beyond theoretical aspirations, working in a multi-stakeholder context to achieve real progress. The PEOF has been organised annually since 2018 in the context of the IMI PARADIGM project, as a joint effort involving three European initiatives: PARADIGM, Patient Focused Medicines Development (PFMD) and the European Patients’ Academy (EUPATI).

The 2018 and 2019 editions were organised as face-to-face events in Brussels that welcomed people from all over Europe and from different stakeholder groups. In 2020, the PEOF was launched in June, as a series of virtual events. PEOF2020 aims to provide a holistic perspective of patient engagement, the landscape and actors. It is also fostering collaboration and co-creation, while breaking down fragmentation and silos that are often present in patient engagement work. The first virtual session of the PEOF2020 took place on 25 June and the closing session will take place on 23 November. Several other sessions are taking place between these dates, on a wide variety of topics, including: tools and recommendations for effective patient engagement; methods for monitoring and evaluation of impact and outcomes in patient engagement activities; and fair market compensation for patient input.

The following sessions have been dedicated to presenting the results of the PARADIGM project:

**25 June**
One of the parallel sessions was dedicated to presenting three of the PARADIGM patient engagement tools that can be used for planning and reporting patient engagement activities.

**7 July**
In one of the parallel sessions, three of the PARADIGM tools that could be used for conducting patient engagement activities were presented.

Some thoughts from the organisers

“Patient engagement in medicines development is multiform, with as yet unmet needs from all actors involved. At the PEOF2020, PARADIGM showed its work to make patient engagement easier for all, with the tools and the Patient Engagement Toolbox that we developed in the past 30 months. Our public private consortium is proud to have provided some of the most needed resources to systematise and sustain a meaningful patient engagement ecosystem. The PEOF has proven its raison d’être and its value to the community at large, and so we are at work, at EPF with PFMD and EUPATI, to pen down a PEOF2021 on everybody’s agendas! It is a challenge that will require resources and commitment from all stakeholder groups.” *Mathieu Boudes, PARADIGM*

“The PEOF reflects a true multi-stakeholder approach, which is crucial to tackle the huge challenges related to implementing meaningful patient engagement. It provides a unique opportunity to share knowledge and information – and plays a key role in shaping the future of the patient engagement landscape. EUPATI is proud to be part of this initiative and bring the importance of patient training into the conversation.” *Maria Dutarte, EUPATI*

“PFMD’s vision for the PEOF was to truly make it open to all stakeholders and ensure that it differs from all the other congresses with the aspect that you can participate in co-creation by joining the sessions. We are so proud to have been able to bring this concept to the audiences since 2019 with a great reception from the audience. Thanks to the collaboration and shared purpose of co-organisers PFMD, PARADIGM and EUPATI to make the event the best we could, the PEOF has been received with high interest and an even better reach globally. We hope you’ve been able to join us in our past sessions and will be able to join the last ones this year, still to come in October and November. See the agenda and register now, there’s still time!” *Chi Pakarinen*
There were flash presentations on: the sustainability roadmap for the patient engagement ecosystem; patient engagement agreements explained; and patient engagement in medicines research and development (R&D) in the Central Eastern European (CEE) Region.

10 September

The session was dedicated to presenting the PARADIGM Patient Engagement Toolbox and the Patient Engagement Monitoring and Evaluation Framework.

The presentations and audio recordings of these and all other PEOF sessions are available at: https://www.patientengagementopenforum.org/#2020agenda

The final sessions of the PEOF 2020 will be held on 5 November (on regulatory aspects), with the concluding session taking place on 23 November.

Information about registration for these sessions is available at: https://www.patientengagementopenforum.org/#2020agenda

Acknowledgement

The PARADIGM project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 777450

“We are proud to have provided some of the most needed resources to systematise and sustain a meaningful patient engagement ecosystem. The PEOF has proved its raison d’être and its value to the community at large.”

Mathieu Boudes, PARADIGM

Our mission is clear. We are pioneers in neuroscience.


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Celebrating one year of the RADAR-AD Patient Advisory Board

RADAR-AD is a collaborative research initiative that explores the potential of mobile and digital technologies to improve the assessment of Alzheimer’s disease (AD).

RADAR-AD is a European project funded by the Innovative Medicines Initiative (IMI). RADAR-AD is looking at two very important areas in Alzheimer’s disease (AD), namely functioning and technology:

- The term “functioning” refers to the activities a person carries out in his/her daily life. RADAR AD, will look at the impact that having Alzheimer’s disease has on a person’s functioning and how the way in which a person functions may change.
- RADAR-AD is also exploring how existing widely-used technology (e.g. smart phones, smart wristbands/fitness trackers, home-based sensors) could be used to measure the changes in a person’s functioning.

The project kicked off in January 2019. The involvement of people affected by AD was crucial for the project from the early days, as they could bring a unique perspective to the research and could actively and meaningfully contribute towards several aspects of the project. To involve people affected by AD in an appropriate and significant manner, RADAR-AD set up an international Patient Advisory Board (PAB) in March 2019.

This work has been led by Alzheimer Europe in close collaboration with project partners and was developed within the framework of Public Involvement (PI). PI is about carrying out research ‘with’ or ‘by’ members of the public (e.g. people living with the condition, their carers/supporters and the general public), rather than ‘to’, ‘about’ or ‘for’ them and should be conducted in such a way that it promotes their meaningful and active involvement.

Who is involved in this work?

The PAB was set up in March 2019, only a couple of months after the project officially kicked off. This was a very important decision as it has allowed PAB members to have input from the very early stages of the project in a timely and meaningful way.

The PAB is composed of people affected by dementia. This includes people with Mild Cognitive Impairment (MCI) and carers. People with dementia who are members of the PAB are all also members of the European Working Group of People with Dementia and the supporters/carers involved in RADAR-AD are the people who support them in their PI work with Alzheimer Europe. In addition, two men with MCI, both living in the Netherlands, and their wives have joined the PAB. A small group of people with MCI from Greece have also provided feedback to some of the consultations.

Work of the PAB over its first year of life

The work of the PAB is based on a person-centred approach whereby each member, after receiving information about the project and the different opportunities for involvement, can decide what type and level of involvement they want to have or is more suitable.
for them. A “core” group was formed with a few members with a special interest on the topic, who were also willing to collaborate more closely and frequently with the project.

There have been several opportunities for interaction between the PAB members and the RADAR-AD team, both face-to-face and by providing feedback in writing.

Examples of involvement
- During the first face-to-face meeting of the PAB, which took place in March 2019 in Luxembourg, members had the chance to learn about the project and provided input related to:
  - functioning from the perspective of people affected by dementia
  - consideration from the perspective of people affected by dementia for the selection of the devices to choose for the trials
  - protocol of the different trials planned in the project
  - involvement of other people affected by Alzheimer’s disease in focus groups in different countries.

- The PAB provided feedback by email during May and June on additional questions linked to device selection and reviewed the Participant and study partner’s Informed Consent Form sheets.

- During the June 2019 meeting in Brussels, they participated in a group discussion on ethical and social concerns linked to the project.

- In August 2019 (Brussels) discussions revolved around the topics of vulnerability and stigma in the context of the project.

- The meeting in December 2019 (Brussels) was dedicated to the RADAR-AD trial, which was planned to start in the first trimester of 2020. The group discussed the possible barriers and facilitators for recruiting and retaining participants in the trial. Similar discussions were also held with people with Mild Cognitive Impairment (the Netherlands and Greece).

- In February the PAB discussed specific ethical issues linked to data privacy and some members were participated in one-to-one with the RADAR-AD.

Four members of the PAB had planned to attend the first General Annual Meeting of the project.

Unfortunately, due to the COVID-19 pandemic, the face-to-face meeting was cancelled and therefore, they were not able to participate in this event.
Conclusions

PI is about creating “partnerships” between researchers and people affected by dementia whereby they all contribute collaboratively. This is a very critical factor for meaningful PI. In the case of the RADAR-AD PAB, the openness and commitment of the PAB members and of the RADAR-AD team has been essential to be able to carry out this work. To date, several RADAR-AD researchers (from all the RADAR-AD work packages) have been involved in the work of the PAB and many of them have been present and co-facilitated the discussions at the meetings. Also, the ongoing nature of this work has helped to create a relationship of respect and trust between the members of the PAB and the project team.

Acknowledgement

The RADAR-AD project has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 806999.

“Patient Involvement is about creating ‘partnerships’ between researchers and people affected by dementia whereby they all contribute collaboratively.”

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Michael Gold, MD
Neuroscience drug development leader at AbbVie
Despite evidence showing that the pathological process of Alzheimer’s disease (AD) starts many years before clinical symptoms appear and evidence about the economic and social value of early detection of AD, people with early AD (mild cognitive impairment (MCI) due to AD and mild AD dementia) remain outside of clinical settings and the diagnosis rates are low.

MOPEAD (Models Of Patient Engagement for Alzheimer’s Disease) is an Innovative Medicines Initiative-funded project contributing to the current drive to shift the paradigm to early diagnosis of AD. The project responds to the global community’s work towards the 2025 dementia goals articulated around four key areas: finding a disease-modifying therapy, living well with dementia, better care, and reducing the impact of dementia.

An innovative project

MOPEAD has been innovative in the sense that it has tested patient engagement models that have until now received little attention: two whereby citizens actively sought out a cognitive test: (RUN 1) Citizen Science – an online pre-screening tool, (RUN 2) Open House – pre-screening tests performed in a memory clinic without a physician’s referral, and two strategies testing patients at risk: (RUN 3) in primary care settings and (RUN 4) in type 2-diabetes / T2DM specialist settings. The persons identified to be at risk of AD were offered referral to a memory clinic for a full diagnostic assessment that they were free to accept or refuse.

Five EU countries were represented in the project: Germany, Slovenia, Spain, Sweden and the Netherlands.

Screening results

For every ten at-risk individuals who were pre-screened during the project, approximately six individuals with MCI due to AD/prodromal AD or dementia were identified. Out of the 2,847 pre-screened individuals, 972 screened positive and 398 were evaluated. In the end, 236 received an AD diagnosis.

In Spain, RUN 4 found a high prevalence of unknown cognitive impairment in T2DM patients. The Diabetes Specific Dementia Risk Score was found to be a useful screening tool.

The presence of associated comorbidities was the main factor for declining referral.

The results varied between countries. Some countries were more successful in pre-screening (Slovenia, followed by Spain). This can be attributed to having much higher numbers of pre-screened individuals in RUN 1 in these two countries.

Overall, more women participated in the pre-screening in all RUNs except for RUN 4. The percentage of individuals eventually diagnosed with MCI or dementia was higher for males in RUNs 1 and 2 while the percentage was higher for women in RUNs 3 and 4.

Screening costs

The screening cost per True Positive (TP) ranged between EUR 3,115 (RUN 1) and EUR 1,190 (RUN 4) (EUR 2,772 for RUN 2 and EUR 1,530 for RUN 3). The cost per screened individual ranged between EUR 103 (RUN 1) and EUR 2,204 (RUN 3) (EUR 212 for RUN 4 and EUR 1,338 for RUN 2).

The cost differences are attributed to the characteristics of the samples: RUNs 1 and 2 aimed at the general population (healthy subjects) while RUNs 3 and 4 aimed at a population at risk with concomitant comorbidities. More subjects need to be tested in RUNs 1 and 2.

There were big country-associated differences regarding the screening costs. RUNs 3 and 4
had lower costs per TP/screened population than RUNs 1 and 2. Nevertheless, the new diagnostic strategies (RUNs 1 and 2) may be valuable after modifications. For example, one challenge in RUN 1 was to get in touch with people who screened positive on-line, and in RUN 2, the cost-effectiveness may improve by integrating RUN 2-screening with diagnosis confirmation at memory clinics.

Engagement of General Practitioners

Despite General practitioners (GPs) key role in identifying cognitive changes and diagnosing dementia at an early stage, MOPEAD partners experienced a mixed range of support when engaging GPs to support the project. To better understand their position, an ad-hoc survey was organised. It revealed that GPs are not opposed to early diagnosis which is predominantly considered to be of value. The results indicate a need for improved education about diagnostic procedures, sufficient time and reimbursement. The attitude towards currently available pharmacological and non-pharmacological treatments seems to affect the handling of early diagnosis.

Ethical considerations

An important step during the project was the disclosure of the diagnosis of MCI due to AD/ prodromal AD. The presentation of the results of clinical, neuropsychological and biomarker data, and the post-diagnostic support, were to be given both orally and in written form, including information to a close relative/caregiver. Referral to other hospital-based specialists or GP specialists was discussed in detail. Management of co-morbidities was generally recommended to be given by their GP specialist.

Finally, it was also important to advise individuals who did not get a diagnosis about follow-up options.

An ethically important part here is that pre-biomarker test counselling should be carried out. Biomarkers might give conflicting results. The patient should also be informed that at present there is no disease modifying treatment available. But they should be made aware that lifestyle improvement measures are always beneficial and usually without negative side-effects.

The gender aspect

Women are disproportionately and increasingly affected by dementia, both as patients and carers. MOPEAD’s results indicate that there is sex and gender variation by country and by RUN. The variations between the four RUNs suggest that different strategies may be more effective for men and for women respectively, which has implications for future studies and strategies.

MOPEAD confirms the findings established in the literature and indicate that sex and gender considerations must be included when developing and analysing tests to detect AD interventions to modify disease progression. Gender considerations must be systematically integrated into AD prevention, diagnosis treatment, care strategies and clinical research.

The Gender Policy Brief that was developed at the end of the project proposes some policy recommendations.

The way forward

MOPEAD’s educational material (Educational Leaflet, infographics, Tips for Coping, videos) was instrumental in raising awareness of AD, memory complaints, risks of cognitive decline and prevention strategies in the general population and can still be used. A number of publications have been produced to share information about the project and its results with a wider audience.

Tackling dementia and AD is an imperative that calls for robust policy action in the context of societal and economic challenges faced by the EU (ageing of the population, increase in the number of persons likely to be impacted by AD and the consequent increase in healthcare and social costs putting in danger the sustainability of the healthcare services). In this context, the project learnings motivated recommendations for policy makers and regulators and ideas for future public education and awareness-raising strategies. To access the resources MOPEAD has produced, visit https://www.mopead.eu

Acknowledgement

MOPEAD has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115985.
Alzheimer Europe speaks to Vice-President Dubravka Šuica about the EU’s plans on ageing demographics

As the population of EU ages and the numbers of people with dementia are projected to rise, Alzheimer Europe spoke to the European Commission’s Vice-President for Democracy and Demography, Dubravka Šuica, about the EU’s plan for a Green Paper on Ageing. In the interview, the Vice-President outlines the focus of the Green Paper and how it will tie into other areas of EU Policy and the next steps for its development and implementation.

What can we expect to see in the Green Paper on Ageing, due for publication 2021?

The Green Paper on Ageing is my first policy initiative emanating from the Commission Report on the Impact of Demographic Change, which we published in June 2020. This report lays the ground for the Green Paper and other future work, by collecting and presenting the evidence on demographic trends and looking at the impact they have on the lives of European citizens. On average, we live longer and healthier lives, even if this may sound counterintuitive given the reality of COVID-19. At the same time, fewer children are being born in Europe, so as a result the overall population is ageing.

By 2070, more than 30% of the population is projected to be aged 65 or older, compared to approximately 20% now. This has a wide variety of impacts on our lives – both at an individual but also population level, as well as at a social and economic level. Therefore, the Green Paper will not only be about older persons but also about how all of this plays out for the younger generation. It will be about ageing and not only about the aged. We will look at social and fiscal impacts, especially in the care sector and at labour markets but we will also approach these issues from a health perspective. While we are still in an early phase of preparations, it is obvious to me that this Green Paper will need to clearly address the challenges that come with an ageing society, as much as pointing to opportunities that we have not identified or exploited enough so far.

Alzheimer Europe recently published the Dementia in Europe Yearbook 2019 which showed that the numbers of people living with dementia will double by 2050 due to significantly ageing demographics in Europe – how can dementia be prioritised in the Green Paper?

Dementia is a disease that hits the elderly in particular. It affects their well-being, their quality of life and also takes a considerable toll on those around them, be it family, friends or carers. With the gradually changing age structure in Europe, this is already becoming a key challenge. Yet, we are also making medical and scientific progress and are learning how to better support persons living with dementia. Since the Green Paper will address in particular the needs that arise in an ageing society, we will take a closer look at what this means for our healthcare and long-term care systems but also intergenerational solidarity and dignity.

“It is crucial that we do not look at the issues of demographic developments, health and social policies in an isolated manner: they are all intrinsically interlinked and condition each other.”

Vice-President of Democracy and Demography, Dubravka Šuica
The COVID-19 pandemic has shown us in stark terms which kind of challenges arise when communicable diseases put health and lives, especially of older persons, at risk. Likewise, non-communicable diseases such as dementia require the preparedness of our care systems. This needs to be an integral part of ensuring our societies and economies are prepared and can manage the impact of ageing societies with their very own health and disease patterns. And effectively, the current pandemic has also highlighted the links between the different challenges: in order to protect the most vulnerable people in society from the novel Coronavirus, many older persons, particularly in care homes, have been subject to stricter containment and isolation measures. They have suffered from loneliness and a lack of social stimulation, which can negatively affect mental health and increase the likelihood of dementia, or exacerbate it when it is already present.

**In terms of competencies for the EU, what do you envisage will be the key areas of focus for the EU in addressing the future demographic changes, particularly in relation to ageing and dementia?**

While many of the competencies in these areas in the hands of Member States, at the EU level we are ready to lead the way by identifying relevant issues and supporting national, regional and local action. There is a lot that we can learn from each other even if the specific challenges and competencies vary from Member State to Member State or even from region to region, or cities to rural areas. During the last months, I have engaged with many governments, parliaments but also non-governmental bodies or initiatives on demographic challenges. There is a vast interest and appetite for exchanging views, best practices and lessons learnt on demographic challenges. This is what we want to facilitate, in order to ensure that we pool resources and seek joint solutions: Europe is at its strongest and best when we work together and pull in the same direction.

Against this background, the Commission also proposed a new and ambitious funding programme on health (the EU4Health programme) as part of the revised long-term budget of the Union. We want to boost the preparedness of major cross-border health threats, strengthen our health systems, and make medicines, vaccines and medical devices available and affordable. This should help us in improving the preparedness for dealing both with communicable and non-communicable diseases in the future.

The long-term budget of the EU and its programmes, such as EU4Health, are currently being negotiated between Parliament, Council and Commission and I very much hope that we recognise the importance of acting together on health.

**How will the EU work to ensure that the work on demographic change, the EU4Health programme, social rights and other relevant work streams are linked together?**

It is crucial that we do not look at the issues of demographic developments, health and social policies in an isolated manner: they are all intrinsically interlinked and condition each other. Ageing societies come with different health patterns, which affects the way people can use their rights or have different needs. Therefore, this Commission has from the very beginning of its mandate worked as a team; my colleagues and I in the College work together in thematic project groups and regularly exchange on those topics, and so do the services. For example, with regard to my work on demography, the Commissioner for Health, Stella Kyriakides, the Commissioner for Jobs and Social Rights, Nicolas Schmit, and I regularly discuss the respective initiatives that we pursue in our respective portfolios and engage closely in topics where our responsibilities converge. Therefore, I am closely working with Commissioner Schmit on the implementation of the European Pillar of Social Rights where aspects on ageing play a key role. At the same time, Commissioner Kyriakides and her services will contribute to the Green Paper on Ageing under my leadership.

**What are the next steps after the Green Paper?**

The Green Paper on Ageing will launch a wider debate and public consultation on the long-term impacts, notably on care, pensions, health and on how to foster active ageing. It means we will engage in an exchange with stakeholders and are looking for their input and experiences. This will help us in preparing the concrete follow-up steps among with the question of care will certainly play a key role. This we will determine during the course of 2021.
Germany launches its new National Dementia Strategy

On 1 July, the German Federal Government announced the launch of the first National Dementia Strategy for Germany. Alzheimer Europe spoke with Franziska Giffey, German Federal Minister for Family Affairs, Senior Citizens, Women and Youth, to find out more about the strategy, as well as with Sabine Jansen, Executive Director of Deutsche Alzheimer Gesellschaft, to hear her reflections.

Can you give us an insight into some of the focus areas of the strategy?

There are about 1.6 million people with dementia living in Germany. By 2050, the number could rise to about 2.8 million. Our aim is that people with dementia are well cared for and remain an active part of our society for as long as possible.

Three of the goals in our strategy are particularly important to me. First of all, we need solidarity and support at the local level. We aim to achieve this by building local networks. Secondly, we need to look at the families of people with dementia. When a loved one develops dementia, professionals must be at hand to advise and support on medical and social issues. For this purpose, we are going to improve the coordination between medical and social care structures. Thirdly, I am working to ensure that we bring about a major shift in social awareness. It was therefore very important to me to start implementing the strategy in cooperation with many different partners. Germany is on its way. But we still have a lot to do in order to actually become a dementia-friendly country.

Does the strategy have a dedicated budget to support the implementation of its objectives?

In the years to come, our society will have to raise billions of euros in order to adapt Germany to the needs of an ageing society and of an increasing number of people with dementia. This is true when planning both at local and at national level and, of course, in the social insurance system, for example when it comes to prevention and care. But also for cultural institutions, religious communities or local sports clubs. The aim of the National Dementia Strategy (Nationale Demenzstrategie) is to do this in a coordinated and focused manner. Networks are central to this. In the next few years, the Federal Ministry for Senior Citizens will fund measures worth two million euros annually in order to create these networks. However, the strategy can only work when all partners make their contribution.

How will the Federal Government be monitoring the implementation of the strategy and how will its impact be measured?

The strategy follows a very targeted approach. It includes a set of about 160 specific measures as well as dates for their implementation. All of these measures will be monitored. In 2026, we will take stock and revise the strategy. But now we are only at the start. We have big plans and a lot to do.

How will you work with Deutsche Alzheimer Gesellschaft (German Alzheimer’s Society) and people with dementia to ensure their voices are heard?

The German Alzheimer’s Society co-chaired the development of the strategy. We, the Federal Government, have been working closely with the Alzheimer’s Society. This partnership is very important to me and, of course, we will continue to work closely together. Achieving the goal of adjusting all areas of life to the needs of an ageing society and of more people with dementia is only possible in a well working team. We are funding the helpline “Alzheimer-Telefon” – an important service in Germany provided by the Alzheimer’s Society. We also cooperate with the German Alzheimer’s Society and various partners in joint projects, for example with the German Olympic Sports Confederation (Deutscher Olympischer Sportbund). All of these cooperations help us to reach people in all areas of life.
In your opinion, what is the most important factor in the success of the strategy?

It is this team spirit that will make the National Dementia Strategy a success. In addition to the Federal Government and the German Alzheimer’s Society, the federal states and municipalities, nursing and health care associations, science and civil society have been involved in the drafting. For the implementation of the strategy many more partners have come together: the rail operator Deutsche Bahn, the German Olympic Sports Confederation (Deutscher Olympischer Sportbund), Martina Voss-Tecklenburg, the coach of Germany’s women’s national football team, in her capacity as dementia ambassador, the German Cultural Council (Deutscher Kulturrat), the two large churches (Protestant and Catholic), supermarket chains such as NETTO and many more. If we manage to make society as a whole realise that we all need to be more aware of the topic, then the implementation of the strategy will work out well. I am sure, it will be a success.

Full details about the German National Dementia Strategy can be found at: https://www.nationale-demenzstrategie.de

Sabine Jansen, Executive Director of Deutsche Alzheimer Gesellschaft, responds to launch of the new National Dementia Strategy

What has been the key driver for the development of the strategy?

In Germany, we have 1.6 million people living with dementia, with this number set to increase in the coming years. In addition to this, we have a lack of professional carers. These are enormous challenges which need a strategy to address them.

What are some of the measures you see as being particularly important in the strategy?

All measures that focus on education of different groups of people, such as public transport workers, the young generation, neighbours etc. are important to create a more dementia-inclusive society. Furthermore, improvements to the medical and care sectors are extremely important.

Does the strategy have a dedicated budget to implement its objectives/commitments?

The strategy itself unfortunately has no budget, however, the ministries that are involved in the strategy have a budget for some of the measures this and next year. We do not know what the budget will be over the coming years. We fear that the consequences of the COVID-19 pandemic might affect the budget for dementia.

How did the Federal Government commit to continuing to work with DAlzG to ensure that the voices of people with dementia are heard during the strategy’s implementation?

DAlzG is member of the steering committee of the strategy which will meet regularly to monitor its implementation. In addition, we regularly discuss the progress with our advisory board of people with dementia.

What do you see as being the most important factor in the success of the strategy?

The monitoring system is important to control the progress of the implementation. The engagement of all actors and of course the money that will be invested, will be very helpful in bringing success.

“...In Germany, we have 1.6 million people living with dementia, with this number set to increase in the coming years. In addition to this, we have a lack of professional carers. These are enormous challenges which need a strategy to address them.”
EU progresses in relation to health, research and budget policy

Since the election of the new European Parliament and the confirmation of the European Commission last year, work has been underway setting out the future programme of work for the EU, in relation to health and research, as well as the Multiannual Financial Framework (MFF). In this article, Alzheimer Europe Policy Officer, Owen Miller, examines the developments over the summer.

In May 2019, elections were held to elect members to the European Parliament, marking the beginning of the transition towards the new cycle of the EU. Following the election, the process of selecting the new President of the European Commission and the European Commissioners began, identifying those who would lead the EU over the coming years.

The changes in leadership and move into the next cycle have taken place during uncertain and unprecedented times, with the global COVID-19 pandemic and the ongoing negotiations about the future relationship of the UK and the EU creating much uncertainty about the future.

Almost 18 months on, negotiations on the EU’s future budget for 2021–2027, the Multiannual Financial Framework (MFF), as well as future policies on health and research, remain under negotiation.

Multiannual Financial Framework (MFF) and the Next Generation EU Recovery Fund

European Commission budget and recovery instrument proposal

Negotiations on the MFF 2021–2027 started as early as May 2018, when the Commission first published its budget proposal. However, little progress was made in the months which followed, with the European Parliament calling for higher spending and the European Council pushing for an overall percentage reduction in spending.

Following the outbreak of the coronavirus and the considerable economic impact on countries, the European Commission produced a new budget proposal in May 2020. In addition to the MFF, the Commission also proposed the Next Generation EU, a recovery fund which sought to address the economic impact of the pandemic.

Combined, the proposal totalled EUR 1.85 trillion, comprised of EUR 1.1 trillion for the MFF and EUR 750 million for the Next Generation EU.

This included a dedicated Health Programme (EU4Health) and commitment to maintain Horizon Europe funding at the levels proposed in the Commission’s original proposal. Details on the funding and contents of these programmes are outlined below.

EUCO meeting

In July 2020, the European Council reached an agreement on the levels of spending for both the MFF and the recovery instrument.

Whilst the total funding package agreed remained largely similar (EUR 1.84 trillion), the implications for funding, both in terms...
of the recovery instrument’s composition as grants and loans, as well as the overall funding allocated for dedicated programmes was significantly altered. This included substantial reductions in the amount of funding allocated for both the health and research programmes.

Parliament reaction

Following the EUCO agreement, the European Parliament passed a resolution stating that they did not accept the European Council’s political agreement on the budget and recovery instrument, whilst additionally noting that they would be prepared to withhold their consent until a satisfactory agreement is reached.

Specifically, the text states that the “proposed cuts to health and research programmes are dangerous in the context of a global pandemic”. The resolution explains that the Parliament will negotiate with the Council in relation to the points within the resolution and calls for an agreement to be reached by October 2020, to allow for a smooth transition to new programmes from 1 January 2021.

Following the EUCO agreement, the European Parliament passed a resolution stating that they did not accept the European Council’s political agreement on the budget and recovery instrument.”

EU4Health Programme

As part of the European Commission budget proposals, a standalone EU Health Programme (named EU4Health) was outlined, with over EUR 9.4 billion of funding in its recent budget proposal (EUR 1.7 billion in the MFF and EUR 7.7 billion included within the recovery instrument). This marked a significant increase on the Commission’s previous for EUR 413 million for a health strand as part of the European Social Fund+.

The EU4Health programme had three overarching general objectives:

- Protecting people in the EU from serious cross-border health threats and improving crisis management capacity
- Making medicines, medical devices and other products, available and affordable
- Strengthening health systems and the health care workforce, including by investing in public health.

Cristian-Silviu Busoi MEP report

The Rapporteur for the EU4Health programme, Cristian-Silviu Busoi MEP, published a draft report, responding to the European Commission’s initial proposal for the programme. In his report, Mr Busoi welcomed the Commission proposal for a stand-alone EU4Health programme, including the significantly increased budget. He reiterated that only a separate and robust programme could ensure the EU had the capacity to respond to future pandemics and health threats, as well as ensuring that health systems are more resilient and able to address current weaknesses.

The report sets out a number of amendments and changes to the Commission’s initial proposal for the EU4Health programme, including:

- A call for a greater focus on disease prevention and health promotion by addressing health risk factors
- Support for the promotion of early diagnosis and screening for both communicable and non-communicable diseases, including neurodegenerative diseases
- The identification of mental health and ageing as a particular challenge, in light of the demographic changes in Europe, including in the areas of early diagnosis, treatment, support and prevention, training of practitioners etc.

Implications of EUCO budget agreement

Following the budget agreement of the European Council, the budget for the EU4Health programme was significantly reduced.

Funding contained in the recovery instrument (EUR 7.7 billion) for the EU4Health was completely removed. Within the MFF, EUR 1.7 billion was allocated for the EU4Health programme, which is broadly consistent with the Commission’s May 2020 proposal.

Whilst this overall represents a quadrupling of the Health Budget compared with the 2014–2020 MFF, many health and patient organisations expressed disappointment at the outcome of the EUCO negotiations.

Whilst negotiations will continue between the Parliament, Council and Commission, as a result of the reduction in funding proposed by EUCO, the EU4Health programme is likely to look significantly different to that proposed by the Commission and to be significantly reduced in scope.
Horizon Europe

The structure and approach of the Horizon Europe Programme was provisionally agreed in April 2019, following agreement between the Parliament, Council and Commission. This resulted in a “pillar system” under which different strands of work would sit. A dedicated health cluster is proposed under the second pillar “Global Challenges and European Industrial Competitiveness”.

Both the Commission’s May 2018 and May 2020 proposals allocated around EUR 94 billion for the Horizon Europe research programme. However, whilst the European Parliament has called for greater spending, it has often been subjected to cuts during the EU CO negotiations on the budget:

- In the MFF, Horizon Europe was allocated EUR 75.9 million, down from the EUR 80.9 billion proposed by the Commission.
- Within the Next generation EU, EUR 5 billion was allocated to the Horizon Europe programme. However, this was a reduction of EUR 8.5 billion from the European Commission’s proposal.

This brings down the total budget for the Horizon Europe research programme to EUR 80.9 billion, a significant drop on the Commission’s proposals. Whilst negotiations will continue between the Parliament, Council and Commission, this development is disappointing.

Proposed partnerships

In addition to the issues around the funding for the future research programme, it is useful to consider that many EU-level dementia-related research projects funded over the past decade have been through the Innovative Medicines Initiatives (1 & 2), a Public-Private Partnership between the EU and pharmaceutical companies.

Whilst there will not be a third IMI programme, three potential health-focused partnerships have been outlined and are under consideration by the EU.

As such, we have outlined details of health-focused research partnerships on page 23 which may be relevant to dementia in the next Horizon Europe programme.

State of the Union Address

On 16 September, President of the European Commission, Ursula von der Leyen, delivered her State of the Union Address, reflecting on the current policy context at an EU level and setting out her policy priorities for the future. Noting the ongoing pandemic and the continuing EU budget discussions, President von der Leyen highlighted the importance of common European actions and the need to build a strong health union.

Amongst other commitments, the President pledged to build a European “BARDA” (an agency for biomedical advanced research and development), as well as calling for a debate on new competences for the EU in the field of health, as part of the forthcoming Conference on the Future of Europe.

In addition, President von der Leyen also sent a Letter of Intent to David Sassoli, the President of the European Parliament, and German Chancellor Angela Merkel, as the Presidency of the Council, in which she detailed the actions the Commission intends to take in the following year by means of legislation and other initiatives, including:

- A legislative proposal on a Data Act
- An Action Plan on the European Pillar of Social Rights (and other areas)
- Legislative proposals to extend the remit of the European Medicines Agency and the European Centre for Disease Control
- A legislative proposal on a European Health Data Space.
European Partnership for Innovative Health (EPIH)

The European Partnership for Innovative Health (also referred to as the Innovative Health Initiative), is not intended as a direct continuation of IMI2, rather it will have a broadened scope with new stakeholders. However, there will be similarities insofar as it will be a public-private collaboration between the European Union and industry, including the European Coordination Committee of the Radiological, Electromedical and healthcare IT Industry (COCIR), the European Federation of Pharmaceutical Industries and Associations (EFPIA), EuropeBio, MedTech Europe and Vaccines Europe.

The initiative intends to:

- Create an EU-wide health research and innovation ecosystem that facilitates translation of scientific knowledge into innovations
- Foster the development of safe, effective, people-centred and cost-effective innovations that respond to strategic unmet public health needs currently insufficiently served by industry
- Drive cross-sectoral health innovation for a globally competitive European health industry.

The EPIH will also cover aspects of health relating to prevention, diagnostics, treatment and disease management.

European Partnership – ERA for Health Research

In the wider European Research Area (ERA), around 80% of national public research investment is made by 15 research funders, including the European Commission. However, there is an identified duplication of procedures and meetings, as well as some diversification of criteria.

This proposed partnership therefore proposes aims to be a platform for flexible joint programming of research programmes, with objectives including:

- Co-designing and jointly implementing co-funding strategies for biomedical research and innovation on selected priority areas of common interest and European added value
- Creating a network of clinical research capacities and research infrastructures, especially EU-funded ones
- Exploring the modalities of data sharing and exploration of health data (e.g. from health care records, disease and patients registries, genomic banks) for new digital health technologies and tools.

This partnership is proposed to begin in 2021/22.

European Partnership on Health and Care Systems Transformation

The partnership, led by Member States, is focused on the transition towards more sustainable, resilient, innovative and high-quality people-centred health and care systems.

It proposes to pool European, national and regional scientific resources to more efficiently address similar challenges related to health and care systems transformation.

Specifically, the objectives of the partnership will be to examine:

- How to implement innovative solutions (organisational, technological) to solve the increasing challenges faced by health care systems
- Provide innovative funding schemes and regulatory frameworks which focus on equity in access to care, care quality, health outcomes and cost-efficiency
- Encourage uptake of new health technologies, cost and accessibility (including risk and vulnerable groups: older persons, immigrants, etc.)
- Involve key stakeholders at local and/or regional levels; citizens/patients, empowerment.

Pre-work on the partnership is tentatively proposed for September 2020, with the partnership then proposed to begin its work in 2021.
Alzheimer Europe hosts online meeting of Government Experts on Dementia

In light of the COVID-19 pandemic, Alzheimer Europe moved all of its scheduled summer meetings to an online platform. This included the meeting of the European Group of Government Experts on Dementia, which discussed issues including national dementia policy developments, as well as national and international work underway to address the COVID-19 pandemic. In this article, we examine some of the key themes discussed during the course of the meeting.

On 4 June, Alzheimer Europe hosted an online meeting of the European Group of Governmental Experts on Dementia comprised of policy leads in charge of dementia policies from national health ministries.

The meeting was attended by 44 people, including representatives of Austria, Belgium, Bulgaria, Croatia, Czech Republic, Denmark, Estonia, Finland, France, Germany, Greece, Hungary, Iceland, Ireland, Israel, Latvia, Malta, Netherlands, Norway, Poland, Portugal, Slovakia, Slovenia, Sweden, Switzerland and the United Kingdom (Department of Health and Social Care and Scottish Government), Representatives from the European Commission (DG RTD and DG SANTE) and the World Health Organization (WHO) also attended.

The meeting was split into two main sections, with the first one focusing on relevant European and national developments with regard to dementia strategies and policies, and the second dedicated to an exchange on initiatives and good practices to support people with dementia and their carers during the COVID-19 pandemic.

During the presentations and discussion in the first section, the group heard that:

- Germany was in the course of preparing and finalising its first National Dementia Strategy, which would be published later in the summer (you can read our article on pages 18–19).
- The Netherlands highlighted that their current strategy would conclude this year, with a new strategy due to be prepared and published next year.
- France outlined some of the tentative findings from the evaluation of its neurodegenerative diseases strategy which concluded in 2019, as well as some of the potential next steps for dementia policy in the country.
- The European Commission provided an update on its proposed standalone EU4Health programme and the Commission activities on the impact of the COVID-19 pandemic on mental health.
- Alzheimer Europe provided an overview of the estimated prevalence of dementia in Europe based on its 2019 Dementia in Europe Yearbook.

In the second section dedicated to the COVID-19 pandemic, the WHO introduced the discussions by presenting the UN framework for the immediate socio-economic response to COVID-19 and the policy considerations developed by the WHO European region on strengthening and adjusting public health measures throughout the COVID-19 transition phases. It was noted that fundamental to the transition was good governance of health systems, data analytics to inform decision making, digital technologies to support public health measures and responsive communication with populations. The WHO also emphasised the need for a balance in exit strategies between infection control, economic considerations and the human rights and personhood of older people and people with dementia, particularly as these groups would likely be the last for whom measures are lifted.

An update on the work of the WHO in relation to its Global Action Plan on Dementia can be found on pages 25–26.

This was followed by short presentations on lockdown exit strategies by health ministry officials from Austria, Finland, Ireland, Israel, Poland, Sweden, Switzerland and the United Kingdom (an article on European exit-strategies can be found on pages 27–28).

Overall, participants reported that following a reduction in the reported number of COVID-19 cases, countries were beginning to ease lockdown measures. During the course of the presentations, a number of common experiences and challenges began to emerge, including:

- The gradual re-opening of in-person support services with additional infection control measures (e.g. fewer people, social distancing etc.)
- The move of many services to online and digital formats to provide continuity of support for people with dementia and carers, e.g. digital consultations, support groups etc.
- The challenges around lifting measures for residential care facilities, including lifting restricted visiting rights for families and carers with examples provided of outdoor visits, time-limited visits and dedicated visiting rooms.
- The emergence, in some countries, of regional approaches to responding to the virus which take into account different levels of government and regional differences in infection rates.

The Group is expected to meet again in December 2020, which is likely to take place online.
World Health Organization shares updates on its progress on work related to dementia

The World Health Organization (WHO) has undertaken much work in relation to dementia as part of the Global Action Plan on the Public Health Response to Dementia 2017–2025. In this article, Stéfanie Fréel and Katrin Seeher of the WHO share an update on the progress of two key areas of work: The Global Dementia Observatory and the Dementia Friendly Initiative toolkit.

The Global Dementia Observatory

In 2017, the World Health Organization (WHO) launched the Global Dementia Observatory (GDO), which contains an online data portal and an interactive knowledge exchange platform. The GDO data portal provides access to key dementia data from Member States across three domains: policy, service delivery, and information and research. Through its 35 indicators, the GDO assists countries in strengthening evidence-based policies, service planning and health and social care systems for dementia.

The GDO also acts as the global monitoring and accountability mechanism, providing support in measuring country progress on dementia actions outlined in the Global action plan on the public health response to dementia 2017–2025. By August 2020, 56 countries had submitted data to the GDO, covering 62% of the world’s population, with approximately 55% being high-income and 45% low- and middle-income countries. GDO data collection is ongoing in over 40 countries, bringing the total population coverage to 81%. Available GDO data informed the first progress report for the 73rd World Health Assembly (WHA) in May 2020. More information from the report of the WHA is available at: https://apps.who.int/gb/ebwha/pdf_files/WHA73/A73_32-en.pdf

The GDO Knowledge Exchange platform

The GDO knowledge exchange platform (GDO KE platform) supplements the data portal. It provides a space for stakeholders to share resources (e.g. policies, guidelines, case studies and examples of good practice), facilitate mutual learning and promote the exchange of good practice for dementia. All resources are submitted by users of the GDO KE platform.

A comprehensive review process consisting of a panel of GDO peer reviewers and a focus group of people with lived experience of dementia ensure that submitted resources meet quality and good practice criteria. Users of the platform are also invited to leave comments and rate the resources.

While the GDO KE platform will be launched later this year, WHO continues to welcome resource submissions and requests to join the GDO peer-review network.

If you have a resource you would like to submit to the GDO KE platform, you can do so at: https://extranet.who.int/dataform/895286?lang=en

If you are interested in becoming a peer-reviewer, you can do so by signing up at: https://extranet.who.int/dataform/456967?lang=en

Towards a dementia inclusive-society: a WHO toolkit for Dementia-Friendly Initiatives

Dementia awareness and friendliness represent one of the seven strategic action areas included in the global dementia action plan. This action area aims to improve communities’ understanding of dementia and create dementia-inclusive societies where people with dementia can live meaningfully, safely and with dignity. More specifically, the global dementia action plan’s global target 2.2 aims to establish at least one dementia-friendly initiative (DFI) to foster a dementia-inclusive society.
society in 50% of countries by 2025, WHO developed *Towards a dementia-inclusive society: a WHO toolkit for DFIs* to help communities and countries achieve this target.

There is a need to raise public awareness and improve understanding of dementia by engaging communities and helping them assume ownership of this endeavour. This is the first step in combating stigma. WHO’s *Towards a dementia-inclusive society: a WHO toolkit for DFIs* supports individuals, communities and countries in empowering people with dementia to remain in, and be a significant part of, their community. The toolkit’s person-centred, rights-based approach is grounded in international commitments such as the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), the 2030 Agenda for Sustainable Development and its Sustainable Development Goals (SDGs) and Universal Health Coverage (UHC).

The toolkit supports individuals working in communities who have little to no experience in programme planning, implementation, management, and/or evaluation, to create dementia-inclusive societies. The toolkit is divided into two parts, the first of which contains introductory information on dementia and a conceptual framework. The second part includes four modules, each featuring a series of practical steps and exercises, focusing on: starting a new DFI, integrating dementia into an existing initiative, monitoring and evaluating a DFI, and scaling-up a DFI. The modules can be used together or separately, and can be adapted to suit local needs and settings.

**“There is a need to raise public awareness and improve understanding of dementia by engaging communities and helping them assume ownership of this endeavour. This is the first step in combating stigma.”**

The World Health Organization (WHO) is an agency of the United Nations working with 194 countries across the world, across six regions, with its headquarters in Geneva, Switzerland. It is primarily concerned with public health matters, including health systems, health through the life-course, and non-communicable and communicable diseases.

Visit [https://www.who.int](https://www.who.int) for more information.
COVID-19 pandemic poses questions for policy makers in supporting people with dementia and their carers

Since the emergence of COVID-19, people with dementia and their carers have experienced particular challenges as a result of government measures to contain the virus. As societies cautiously move towards easing measures, Alzheimer Europe Project Officer Angela Bradshaw explores how these policy responses have evolved throughout 2020.

On 1 December 2019, a man with Alzheimer’s disease developed a fever and a dry cough. Living in Wuhan, China, he was among the first documented cases of COVID-19 – although studies now suggest that SARS-CoV-2, the virus that causes COVID-19, may have been circulating months before that date.

Since December 2019, the COVID-19 pandemic has spread across the globe, starting with south-east Asia before rapidly taking hold in Europe, the Americas, Africa and the rest of Asia. Over 35 million people worldwide have been diagnosed with COVID-19, with almost 1,050,000 fatalities at the time of writing. The excess mortality figures are equally stark, with a recent report estimating nearly 600,000 more deaths than would normally have occurred between the start of the pandemic and the end of July. Nursing homes have borne the brunt of COVID-19, exposing vulnerabili ties in long-term care systems that are often under-resourced and overstretched. To date, almost half of all deaths caused by COVID-19 in hard-hit countries have been among residents of long-term care facilities (LTCF).

These figures illustrate how the COVID-19 pandemic has affected communities, separating people from loved ones and widening inequalities in health and social care. However, without confinement measures implemented across Europe in early 2020, this picture could have been even more devastating; a modelling study published in June estimated that lockdown may have averted over 3 million deaths between February and May alone. In this article, we look back at the progression of the COVID-19 pandemic and the lockdown strategies employed in Europe, in relation to people affected by dementia.

The COVID-19 pandemic spreads across Europe

The first European case of COVID-19 was reported by France on January 24, in an individual with a direct link to Wuhan, China. However, Italy was the first EU country to impose a national quarantine in early March, a fortnight after the identification of several large clusters in Lombardy. Swiftly followed by similar quarantine measures in Spain, France and Ireland among other EU countries, lockdown confined citizens to their homes, closing schools and non-essential businesses, curtailing travel and closing borders. LTCFs shut their doors to outsiders, halting family visits and in some cases, quarantining residents to their rooms. On March 25, the European Centre for Disease Prevention and Control (ECDC) announced that all EU/EEA countries and more than 150 countries worldwide were affected by COVID-19. By the start of April, more than half the world’s population, over 3.9 billion people, were in confinement.

At the height of the pandemic, when France, Italy and Spain were topping global league tables of COVID-19 deaths, EU policymakers and Member States were looking towards a time when containment measures could be lifted. On 15 April, the European Commission published a Joint European Roadmap towards lifting COVID-19 containment measures, identifying when – and how – lockdown restrictions should be lifted. Acknowledging that there is no ‘one size fits all’ strategy, the Roadmap placed a strong emphasis on epidemiology and public health, stating that countries should only consider exiting lockdown once the COVID-19 spread has decreased and stabilised, when there is sufficient health system capacity and when there are test-based monitoring systems in place. Following the principles of mutual respect and solidarity, EU member states were asked to take a gradual approach to deconfinement, progressively phasing in economic and education activities whilst phasing out travel restrictions. Of particular relevance to people with dementia, the Roadmap recommended targeted, long-term measures to protect those with chronic diseases, whilst lifting restrictions for less vulnerable groups.

COVID-19 risk: age is not the only factor

Indeed, health protection agencies realised early on that some groups were much more vulnerable to COVID-19 than others, and that protection of these groups might require specific measures – such as limiting their interactions with people outside the home. Certain countries applied more restrictive measures to prevent COVID-19 infection, with Ireland “cocooning” its senior citizens and England instituting “shielding” measures designed to confine high-risk individuals to their homes. Deemed particularly vulnerable were older people with pre-existing health problems, especially those living in LTCFs. Supporting this risk designation, demographic studies indicated that people aged over 70 may be more than 8 times more likely to die from COVID-19 than people under 50. Unsurprisingly, most countries categorised older people as a high-risk category for COVID-19.
group, especially those with heart, lung, kidney or metabolic diseases.

More surprising was the absence of dementia and Alzheimer’s disease as a high-risk designation, despite many people with dementia being older and having complex health needs. Although it wasn’t clear at the time, emerging evidence now suggests dementia per se may present an increased risk for COVID-19 infection, and a greater likelihood of developing neurological complications and cognitive decline. Alarmingly, recent figures from the UK Office for National Statistics indicate that people with dementia may account for over a quarter of COVID-19 deaths, linked in part to the high COVID-19 mortality rate in British LTCFs. Going beyond mortality figures, COVID-19 has also disproportionately impacted the daily lives of people with dementia and their caregivers. Reports from the WHO, OECD and patient organisations paint a stark picture of worsening cognitive and psychological health as a result of severe disruptions in life routines, reduced access to care services, and limited interactions with loved ones.

**The Joint European Roadmap: a coordinated approach to deconfinement**

Given the far-reaching economic and social consequences of lockdown, countries have been eager to ease confinement measures and gradually return to normality. Following the publication of the Joint Roadmap in mid-April, many central and northern European countries started relaxing lockdown measures. Denmark was among the earliest countries to resume in-person schooling, reopening nurseries and primary schools on 15 April. Around the same time, German non-essential shops were given permission to resume business, and municipal parks were opened to the general public. Wider relaxation of lockdown measures followed in May, with Italian restaurants opening, French schools restarting and several EU countries permitting limited visits to LTCFs. By the middle of June, COVID-19 numbers were low enough that the European Commission recommended the lifting of internal border controls between Schengen states, and some professional sports leagues resumed activities. At the end of June, in his last public address as Taoiseach, Leo Varadkar announced the reopening of places of worship, leisure facilities and hair salons, although “cocooning” was still recommended for vulnerable groups and those aged over 70. A week later, people in England who were shielding were allowed to meet with a limited number of people outside, and by the end of July shielding was paused entirely. Although most EU countries retained restrictions on the size of indoor gatherings, and instituted rules on face coverings and physical distancing, many Europeans were able to enjoy a relatively normal summer.

**A second wave?**

However, as Europe enjoyed one of the warmest summers on record, the WHO sounded an alarm bell over growing infection numbers in countries that had successfully slowed COVID-19 outbreaks in the spring. As summer turns to autumn, it is becoming increasingly clear that Europe is approaching a second wave of the COVID-19 pandemic. Reported cases are reaching record highs in countries such as France and Spain, although deaths are still well below their April peak – in part due to the fact that new cases are predominantly being diagnosed in younger age groups. However, public health experts have warned that this uptick in numbers may soon roll over into older populations, potentially leading to larger death tolls and a return to strained and overextended health and social care systems. As a result, affected countries are gradually re-instituting local confinement measures; for example, Marseille has closed its bars and restaurants, while British care homes in areas with high numbers of COVID-19 cases have moved to stop visiting.

Additionally, governments are facing increasing calls to safeguard people with dementia against the second wave of the pandemic, to ensure that their human rights are respected. Much more is now known about the myriad physical, psychological and social impacts of COVID-19 on people affected by dementia – and how to mitigate some of these impacts using adapted care strategies, telemedicine and in-home therapies. We can but hope that this knowledge will be used to ensure our governments, communities and healthcare systems protect and promote the well-being of people with dementia and their caregivers.

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**Daily new confirmed COVID-19 cases per million people**

Shown is the rolling 7-day average. The number of confirmed cases is lower than the number of actual cases; the main reason for that is limited testing.

![Daily new confirmed COVID-19 cases per million people](image_url)

Source: European CDC – Situation Update Worldwide – Last updated 8 October, 10:05 (London time), Official data collated by Our World in Data CC BY
Kate Lee takes the helm at Alzheimer’s Society

In April 2020, Kate Lee started her position as the new Chief Executive of Alzheimer’s Society (UK). She reflects on new beginnings and on leading during the COVID-19 pandemic.

What made you decide to take the position as Chief Executive Officer at Alzheimer’s Society?

I have worked in charities my whole career and feel passionately about their work and importance in UK society, so I was excited by the challenge of leading a large not for profit organisation. However, my decision went further than that.

My mum was diagnosed with dementia 16 years ago and my grandmother before her. Dementia has therefore dominated my life for a long time and robbed me of some of my most special and important relationships. I feel I understand some of the challenges dementia brings first hand and wanted to bring the combination of my experience and passion for the cause together into this incredible opportunity.

What are your main hopes and aims for the future of the organisation?

Right now our focus is very much about surviving COVID-19, ensuring that the organisation is as responsive as possible to people living with and affected by dementia as they struggle with this rapidly changing environment. We have seen so many positive things over the last few months: better collaborative working, a clearer focus on the things that evidence tells us makes a difference and, as an organisation, working (almost!) seamlessly as one team.

I want to build on all those things in future, to create a vibrant organisation focussed on impact that is also a very credible partner of choice for other organisations and professionals working to reduce the impact of dementia.

You started in this new role during the early stages of the COVID-19 pandemic and the public health crisis it has brought about. How has it been for you to take the helm during this difficult period, with the uncertainty and anxiety it has brought as well as the impact it is having economically, politically and socially? Have there been positives as well as negatives?

Well, it has certainly been a challenge. I am a very visible leader, who loves meeting people, so doing my first six months purely sat in my little spare bedroom hasn’t felt the greatest way to start a new role. There have been some positives, as I have already mentioned, but we have also had to cut some services, make redundancies and, obviously, received almost daily news of the devastation COVID-19 has brought to families affected by dementia, particularly those in residential care. It has been a very difficult, sad and frustrating time for all and it is credit to the Alzheimer’s Society team that they have achieved such amazing results despite the pressures. I am in awe!

With Britain having left the EU, Alzheimer Europe is keen to continue its collaboration with Alzheimer’s Society, and other UK colleagues, to ensure dementia is a priority at national and European level. How do you see the relationship and collaboration evolving between Alzheimer’s Society and Alzheimer Europe, as well as other European organisations? Does Alzheimer’s Society plan to maintain the same level of collaboration in the future?

Dementia is a global issue, and we will continue our long held collaboration with Alzheimer Europe to help maintain dementia as a priority in Europe. Working with Alzheimer Europe and its other member organisations is essential in sharing understanding of how we are all tackling the issues that people face, as well as what we are doing in terms of influencing and engagement to better develop national responses through service development, support and government-led strategy. Continuing to work with European colleagues is not just about the EU and in terms of research, Alzheimer’s Society and Alzheimer Europe have a long history of collaboration both directly and indirectly through other European funders, which we look forward to continuing.

Research is a borderless endeavour and ensuring knowledge and expertise is able to move freely must remain our priority. There will be opportunities to fund collaboratively across borders, but also the need to support researchers working in different jurisdictions. Only by continuing our partnership will we tackle the global challenge of dementia.

Kate Lee

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Kate Lee
Vienna forms a working group of people with dementia

Angela Pototschnigg, Austrian member of the European Working Group of People with Dementia, has joined a new dementia working group in Vienna. She tells us about the group, which is called “Über den Berg kommen”, meaning “Turn the Corner”.

I was about 57 years old when I noticed that something was happening to my brain. I had trouble concentrating, my memory was not working as I was used to, mistakes were constantly happening in my professional work and I needed much more time to get things done. The burnout that was diagnosed at first, soon turned out to be a misdiagnosis. I had to give up my job and retire early. In order not to fall into a black hole, I started looking for supportive possibilities: I was offered handicrafts, painting and singing – but these things never interested me before in my life. So, I know how difficult it is to find an adequate support, from someone who has a great deal of knowledge about dementia, and who uses and passes on this know-how to accompany affected people in their everyday life, so that a self-determined life is largely possible.

I can well remember what a bad mental state I was in, because it is hard to cope with this diagnosis. But I was lucky and in my search I came across a support group for people with dementia. From these experiences I know how great and relieving it can be to have conversations with other people affected. I can now pass on exactly this experience in peer-to-peer talks that I have been offering since 2019 under the umbrella of Alzheimer Austria.

The idea for the group is born

Based on the experience and feedback from peer-to-peer counselling, the idea was born to offer younger people affected by dementia and people, who have just been diagnosed, a platform for mutual exchange and joint activities. A further concern is to strengthen self-esteem and encourage people to talk about their own worries, needs and wishes.

“Turn the Corner” (in German “Über den Berg kommen”) started at Alzheimer Austria in February 2020, with a lot of plans for the group meetings...

Many activities are planned

Experts from all over Austria are invited to give us lectures in simple language on various important topics to inform about possibilities that can support us in everyday life and in special situations.

It’s about additional forms of therapy apart from drug therapy, such as occupational-, physio- and speech-therapy, as well as psychotherapy. Subjects such as memory training, exercise and nutrition, support in using technical equipment are also discussed. We will learn how a preventive power of attorney or a “living will” can be drafted so that our self-determination isn’t lost if we are no longer able to communicate.

There will also be presentations on basic and human rights, on our right to assistance at work, and on protection against discrimination. A neurologist will speak on diagnosis and drug therapy. After the lectures we can get answers to our questions.

I think it is particularly important for us, to get knowledge and information about the topic of dementia, because this way we can learn to deal better with the disease and to develop strategies. That’s exactly what I was looking for years ago, and I think that’s what happens to many people affected by dementia!

Being part of this project means a lot to me. This is about us! Our perspective is valued and our understanding of dementia, with its many stumbling blocks, is supported by knowledge, information, exchange and group discussions.

COVID-19 gets in the way...

There were four of us at our first meeting on 20 February 2020. I liked getting to know people who share similarities with me, and we were able to have good discussions. All participants were looking forward to coming back.

Unfortunately, the coronavirus and the lockdown intervened and a next meeting was out of the question, for the time being.

…but not for long

I was very happy when the activities at Alzheimer Austria were able to start up again, carefully, and on 18 June the time had come for our next “Turn the corner” meeting to take place!
That afternoon, occupational therapists were invited to inform us about the goals we can achieve through occupational therapy: The aim is to maintain our independence for as long as possible, to be able to maintain social contacts, and to prevent our withdrawal; as well as to make everyday situations clearer and simpler, and learn to manage stress. The question “What do you really enjoy doing?” is also asked in occupational therapy, because an important goal is to support us in things and activities that we enjoy.

The next meeting after the summer break started in the third week of August, this time we were nine participants. A psychologist, the head of the Academy for Memory Training in Salzburg, gave a presentation on holistic memory training.

As many brain functions as possible, such as perception, concentration, memory, word finding, orientation and creativity should be stimulated, she said. I already have experience with it myself, because I’ve been doing memory training for about a year. For many, however, the topic was new. She gave us suggestions on how we can also train our brains in everyday life.

“It’s not about practicing things that are particularly difficult for us, to the point of exhaustion, but rather starting with what we enjoy and where our interests are going. I liked her advice to “be patient, indulgent and tolerant” with our brains, because after all it still serves us well, plus we learned that stress and self-reproach damage our brains. Another thing I found really good to know, which she pointed out, is that a healthy brain also has its gaps!

**Alternating meeting types**

I particularly appreciate the concept of the “Turn the corner” project where meetings with lectures and meetings for exchange and discussion alternate. I think that’s very important and gives us the opportunity to get to know each other better and to learn from each other.

Johanna Püringer is responsible for the organisation and management of the meetings. Her presence at the meetings is useful to ensure moderation and a good process.

**“Being part of this project means a lot to me. This is about us! Our perspective is valued.”**

The Diplomatic Academy of Vienna dedicated its annual charity ball to the new Turn the corner group, February 2020, Vienna

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**“I particularly appreciate that the ‘Turn the corner’ project alternates meetings with lectures, and meetings for exchange and discussion. It gives us the opportunity to get to know each other better and to learn from each other.”**
Campaigning to “Bring Dementia Out”

Patrick Ettenes is an LGBT person living with young onset dementia. He shares his story and both he and Claire Days of the LGBT Foundation tell us more about the “Bring Dementia Out” campaign taking place in the United Kingdom.

Patrick’s Story

At the fruitful age of 31, I found out some life changing news, that soon I would be the youngest person in the UK with one of the rarest forms of dementia – Frontal Lobe Atrophy (Frontotemporal Dementia).

I was struggling with my diagnosis along with multiple mental health issues. After a few months of trying to come to terms with a diagnosis, I started going to support groups with the Alzheimer’s Society. I soon realised that there was no support for someone from the LGBT community, particularly a man of my age, living alone, with no family or support networks. Struggling with all the condition could bring was worrying.

Using my connections and my struggles, I started advocating and asking to do something for the Alzheimer’s Society. I set up one of the world’s first LGBT Dementia Networks, but living with a condition along with people working full time, things fell by the wayside.

Over a few years the Bring Dementia Out Project was born (developed by the Innovation Team at Alzheimer’s Society), and I was asked...
to assist the project. As a person living alone with the condition I felt empowered to make those like myself without a voice, heard. The amazing Natasha Howard (Senior Innovator, Alzheimer’s Society) led the project, and for two years the innovation took flight. I narrated the short film highlighting the issues that people from different walks of life within the LGBT community face around living with dementia.

“I can’t stress enough that so many LGBT people think of dementia as a taboo; they are too frightened to think of the possibilities of getting such a condition, because who will help us if we did?”

Patrick Ettenes

And the interesting part starts here: I live in a property managed by The Guinness Partnership, whom I had also met years back at a meeting at the Alzheimer’s Society. The amazing Wendy Wells (Head of Policy and Business Implementation / Housing & Dementia Project Lead, The Guinness Partnership) and I became closer. As I had an established connection with LGBT Foundation (through my many years of working with them), I suggested that The Guinness Partnership and LGBT Foundation form a new partnership.

You see, I’m very good at knowing where things should go and had envisioned that the LGBT Foundation would be a good fit for this new programme. But of course, funding was needed. And funny enough, The Guinness Partnership was looking to support a new programme.

I presented the project to them and suggested whom better to help their own tenants. The LGBT Foundation had the perfect location and staff (whom have saved my life many times over), and I knew they would save many other lives if we could make this work.

This project is a child of mine; a child to make sure others like myself – older or younger, single or not – do not feel ALONE.

I can’t stress enough that so many LGBT people think of dementia as a taboo; they are too frightened to think of the possibilities of getting such a condition, because who will help us if we did?

I hope this project will continue to grow, like a kid it will branch out and gather information, services, link in with other networks, making LGBT issues and complications around dementia known, heard, understood, to educate the services that would assist us, understand and reach down in their souls again, and find that empathy that we lose within establishments, and realise that we are frightened... but soon no more.

I as a single LGBT person, who could die anytime, and know that my life wasn’t in vain, because a legacy to help my community continues to make everyone feel they aren’t alone with this disease.

Bring Dementia Out campaign

The next iteration of this programme seeks to address the additional challenges faced by LGBT people living with dementia, and those supporting them, in ensuring that they receive the support they need when they need it. The programme is led by LGBT Foundation, in partnership with the LGB&T Partnership, National Dementia Action Alliance, and Switchboard (Brighton & Hove), and supported by the Guinness Partnership. We continue to be grateful for the advice and knowledge received from the Alzheimer’s Society.

Beginning in December 2019, the programme focuses on: building knowledge and visibility of LGBT people living with dementia and the additional challenges they may face when accessing housing and care providers, and improving support for LGBT people living with dementia to continue to live well. We are working with LGBT people living with dementia, and those supporting them, to ensure their priority concerns inform the development of training for the housing and care sectors. The first stage of this training (a 90 minute webinar) is due to be rolled out to employees of The Guinness Partnership in September, followed by a broader roll out to the staff and volunteers of other housing and care providers in October.

The second stage of the training offer will be available early next year (due January 2021), and will see the development of a downloadable self-guided learning package along with guidance, sample activities/posters,

“The programme focuses on: building knowledge and visibility of LGBT people living with dementia and the additional challenges they may face when accessing housing and care providers, and improving support for LGBT people living with dementia to continue to live well.”

Claire Days, LGBT Foundation
and additional signposting to services and support for LGBT communities.

One of the main priorities of this programme is to improve the support offered to LGBT people living with dementia. The main obstacle to providing the right support at the right time is the lack of visibility of LGBT people living with dementia as they are often not identified within the service. Effective monitoring is vital to ensure individuals are not hidden, and so relevant support and advice can be offered. We don’t actually know how many LGBT people are living with dementia, so we can only estimate numbers based on the limited information we do have. We know that there are currently 850,000 people living with dementia in the UK based on figures from the Alzheimer’s Society.

One government estimate (Dept. of Trade & Industry ‘Final Regulatory Impact Assessment: Civil Partnerships Act’ 2004) states that 5–7% of the UK population identifies as LGB (Lesbian, Gay, Bisexual), and a further 1% of the UK population are trans and/or gender variant (GIRES, 2012). Based on these figures, we can estimate that there are as many as 68,000 LGBT people living with dementia in the UK. However, another estimate from Phillip Harper (Coventry University Group) places this figure at 85,715 lesbian and gay people living with dementia alone (not including bisexual and trans people living with dementia) – this is based on work published by Semlyen in 2016, who states: “It can be believed that there are 1.2 million older gay and lesbian people in the UK.” and Alzheimer’s Society which tells us that 1 in 14 older people will develop dementia. Without accurate and consistent monitoring we are working to massive margins of error.

Early feedback from the delivery of pilot training sessions at The Guinness Partnership suggests that monitoring might be an area in which there is a lack of confidence; knowing how to ask the question in a sensitive and professional way without causing offence might be a concern for some. We know this is a concern across sectors, and the Pride in Practice programme at the LGBT Foundation delivers a module just on monitoring in the training academy.

Monitoring is touched on briefly in the webinar training for Bring Dementia Out, but will be expanded on for the self-guided learning package as we recognise its importance. A common saying around the LGBT Foundation is “We don’t count unless we are counted”.

One of the main challenges faced by LGBT people living with dementia when accessing mainstream services and support is a lack of awareness of the experiences of LGBT people, particularly as it relates to healthcare inequalities.

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One of the main challenges faced by LGBT people living with dementia when accessing mainstream services and support is a lack of awareness of the experiences of LGBT people, particularly as it relates to healthcare inequalities. In 2020, the LGBT Foundation published a report titled “Hidden Figures”. This report highlights many of the healthcare inequalities experienced by LGBT people and is a culmination of extensive research with LGBT people and healthcare professionals. Many of these inequalities can be seen as contributing factors to the development and progression of dementia. Some examples of this include:

- 23% of LGBT people have at one time witnessed anti-LGBT remarks by healthcare staff (fear of discrimination can lead to LGBT people not seeking help, leading to later diagnosis).
In 2017, 1 in 6 LGBT people reported drinking almost every day in the last year, compared to 1 in 10 adults in the general population who report drinking alcohol on 5 or more days per week (Alcohol Related Brain Damage may be more prevalent amongst LGBT people).

42.8% of LBT women said they had experienced sexual violence compared to an estimated 20% of all women in the UK (trauma and poor mental health can be factors in the development and progression of dementia).

Along with healthcare inequalities, the LGBT community has a complicated legal and social history. Before 1967, homosexuality was illegal; the Sexual Offences Act, 1967, decriminalised homosexual activity between consenting males over the age of 21 (in private).

Over many decades, LGBT communities have had to fight for their rights (e.g. marriage and adoption equality) whilst facing legislative and social discrimination from the government and the wider community. For example; Section 28, enacted in 1988 and repealed in 2003, prevented the “promotion” of homosexuality by schools and public bodies, and referred to LGBT families as “pretend families”. This means that many young LGBT people did not have access to the support or knowledge they needed, but also forced many LGBT teachers (as well as other professionals) to hide their identity for fear of losing their jobs and not being able to offer support to LGBT young people in their care. For many LGBT people living with dementia, the loss of more recent memories may mean they do not remember that they have come out, or who knows about their identity, or that they have legal protection from discrimination. We need to understand at least a little about this in order to ensure we can offer the reassurance and support needed.

In addition to the training package, we are raising the visibility of LGBT people living with dementia through developing relationships across the housing and care sectors. We have written numerous articles and blogs, as well as meeting with organisations and individuals seeking to support LGBT people living with dementia.

The last few months have been difficult for many people and organisations, with COVID-19 still a concern for many people, ensuring we are reaching and supporting people is ever more vital. Research from the Alzheimer’s Society tells us COVID-19 has had a particularly negative impact on people living with dementia (dementia is the main underlying cause, representing 1 in 4 COVID-19 related deaths in the UK). Prolonged isolation has also been noted as a factor in the progression of symptoms in those living with dementia. Now, more than ever, we need to ensure that those who are most invisible in our services (including LGBT people living with dementia) are not forgotten.

We need to do everything we can to ensure that all people living with dementia are able to live well.

Get in touch

If you would like more information about Bring Dementia Out, or if you would like to access the training, please contact claire.days@lgbt.foundation

Claire Days

Claire Days is the Bring Dementia Out programme coordinator, and is leading on the development of the training package. Claire has worked in the charity sector for more than 10 years, developing and delivering community focused programmes with an emphasis on the engagement of underserved and under-represented communities.

Patrick Ettenes

Patrick is a writer, consultant and lived experience advisor for dementia. Patrick is one of the youngest people living with dementia in the UK, and passionately advocates for the inclusion of all people within dementia services and care. Patrick is the winner of the LGBT Role Model award from the National Diversity Awards, 2019.

@PEttenes

LGBT Foundation

“We are LGBT Foundation – securing a safe, healthy and equal future for all LGBT people.”

https://www.lgbt.foundation

@LGBTfdn

@PEttenes
Lancet Commission identifies 12 modifiable risk factors that could account for 40% of dementias

In 2017, the Lancet Commission on dementia prevention, intervention and care identified nine modifiable risk factors which might contribute to a person’s risk of developing dementia. Their recent update, published this summer, adds three further risk factors to this list. We also speak to the lead author, Gill Livingston, and ask four experts to comment.

Over the last three decades, the search for a drug that can effectively treat the underlying causes of dementia has been elusive, with few positive developments to report. However, despite the absence of an effective disease-modifying therapy, there is growing consensus that concrete steps can still be taken to reduce the risk of developing dementia.

Indeed, according to the recent Lancet Commission on dementia prevention, intervention and care, modifiable risk factors may hold the key to lessening your chances of developing dementia. Defined as factors that can be reduced or controlled through altered behaviour, modifiable risk factors include lifestyle habits such as smoking, and treatable conditions such as type 2 diabetes.

At the opposite end of the spectrum are unmodifiable genes such as ApoE4, and the most well-established risk factor for Alzheimer’s disease and dementia: increasing age. Encouragingly, a subgroup analysis of 1109 participants in the Finnish FINGER trial suggests that adopting healthy lifestyle habits may diminish the negative effect of ApoE4 on cognitive function, reinforcing the importance of understanding and addressing modifiable risk factors for dementia.

So what are the key modifiable risk factors associated with dementia? In their original report, which was published in 2017, the Lancet Commission identified nine lifestyle habits and treatable conditions linked to increased worldwide dementia prevalence. In order of importance, these were hearing loss, less education, smoking, depression, physical inactivity, hypertension, social isolation, obesity and diabetes.

In their recent update to this report, Professor Gill Livingston and coauthors have added three more modifiable risk factors to this list: excessive alcohol consumption, traumatic brain injury and air pollution.

Midlife hearing loss associated with cognitive decline

To identify these risk factors, the Lancet Commission performed a comprehensive analysis of hundreds of research studies and publications, including the recent large-scale FINGER, PreDIVA and MAPT trials on multidomain interventions for cognitive impairment.

Studying risk factors at different stages across the lifespan, Professor Livingston and colleagues identified risk factors in early life, midlife and later-life that could be targeted by individual-level and policy interventions. For example, maintaining high levels of cognitive stimulation in early life could reduce dementia risk by 7%, based on robust evidence showing that those with higher childhood education levels and lifelong educational attainment are less affected by dementia.

In midlife, hearing loss was shown to have the most substantial effect on dementia prevalence, potentially accounting for 8% of cases, followed by traumatic brain injury (3%) and hypertension (2%). Traumatic brain injury (TBI), defined as injuries such as concussion or skull fracture, was added to the list based in part on findings from a Danish population study of almost 3 million middle-aged adults, showing that people with a history of TBI were 24% more likely to develop dementia.

Several modifiable risk factors were identified as having an impact in late life; in particular, smoking (5%), depression (5%) may contribute substantially to dementia. Social isolation (4%) also has a substantial impact on dementia risk; in a UK 28-year follow-up study of over 10,000 older people, frequent social contact in late middle-age reduced the odds of developing dementia by 10%. Together, these twelve risk factors across the lifespan may account for around 40% of worldwide dementias.

The existence of potentially modifiable risk factors for dementia has important ramifications: it means that prevention of dementia may in part be possible through a public health approach, via the implementation of lifestyle interventions targeting these risk factors.
When I began my career, the thought that it might be possible to prevent dementia by modification of risk factors was not on the horizon. I remain delighted and surprised to see how populations which have reduced smoking, increased education and treated cardiovascular disease are already showing huge reduction in the incidence of dementia.

I think there are many implications of the research featured in the 2020 Commission. I want to pick out three. The first is that these risk factors cluster in more disadvantaged populations, minority groups and those in low and middle income countries. These groups could potentially benefit more from modification of risk factors than others who are more advantaged. However, there are large numbers of people worldwide who have not yet begun to see this benefit. This indicates how much could be done, quickly, to make a difference and reduce dementia incidence further.

The second key implication is that policymakers and public health officials can do the most to make a difference, as risks are often determined by a person’s lifestyle habits and environment. These include, for example, ensuring that the environment is not obesogenic, by ensuring that obesogenic food is not the cheapest and most readily available option. Together with initiatives to encourage physical exercise, this could reduce weight, diabetes and high blood pressure. Other beneficial policy actions could encompass increased education, seatbelts, helmets for cycling and banning smoking in public places. Meanwhile individuals can do much to reduce their risk, and in an enjoyable way – for example, by seeing friends and family, drinking in moderation and doing physical activities they enjoy.

The third key implication is that in the oldest and most physically ill individuals, less neuropathology is required for them to develop dementia. This cognitive vulnerability is the opposite of cognitive reserve, and indicates that bodily health is inextricably linked to brain health. Addressing bodily health is essential to reduce cognitive vulnerability.

We have learned a considerable amount about preventing and delaying dementia. The stakes are high and the time for action is now!

“The Lancet Commission confirms that diabetes persists as an important risk factor for dementia in elderly people. Indeed, studies have shown that people with type 2 diabetes are almost twice as likely to develop cognitive impairment, and experience more rapid cognitive decline than peers without diabetes. Tackling type 2 diabetes represents a promising target for a precision health approach to prevent dementia. However, we need more accurate ways to identify people with type 2 diabetes who are at higher risk of developing dementia. In RECOGNISED, we are using the retina as a tool to non-invasively screen the population, to identify the prodromal stages of dementia in a precise and patient-centred way.”

Rafael Simò, RECOGNISED
“Despite the large disease burden caused by obesity and type 2 diabetes, we still lack any substantial insights into the mechanisms underlying the dementia risk increase brought about by those factors. While vascular problems are often blamed, an alternative hypothesis is that altered insulin signalling in the brain explains the cognitive decline. Insulin not only regulates glucose and lipid metabolism in the brain, it also plays an important role in learning and memory. In PRIME, we aim to generate the dearly-needed insights into the role of insulin signalling in the association between diabetes, obesity and dementia.”

Barbara Franke, PRIME

“The fact that the new Lancet report supports adding air pollution to the list of modifiable risk factors for dementia clearly indicates a strong connection between air quality and dementia. However, we still lack detailed understanding of the connection between the two. In ADAIR, we will address key questions such as how air pollutants impair brain health, and identify biomarkers to pinpoint high-risk individuals. Our hope is that these people could be identified prior to disease onset, allowing preventive measures to be targeted to at-risk populations.”

Katja Kanninen, ADAIR

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).
Brain Health Scotland initiative is launched

Developed in partnership with Alzheimer Scotland, and funded by the Scottish Government, Brain Health Scotland (BHS) is a new initiative launched on 14 September 2020. It aims to inspire and empower people to protect their brain health and reduce their risk of diseases, including dementia. Executive Lead, Anna Borthwick tells us more.

Brain Health Scotland

Your brain is who you are. It is your thoughts and feelings, your knowledge and memories. It is curious and creative, and without it you are lost.

At Brain Health Scotland (BHS) our mission is to inspire and empower everyone in Scotland to protect their brain health and reduce their risk of diseases including dementia.

We work with all ages, across the whole of Scotland, to provide all you need to protect your brain and to join the effort to understand more about this amazing part of who you are.

What we do

Developed in partnership with Alzheimer Scotland, and funded by the Scottish Government, Brain Health Scotland provides:

- Expert advice about brain health research, policy and healthcare
- Promotion of positive brain health in collaboration with Public Health Scotland and other partners
- Support to ensure health professionals in Brain Health Services can provide personalised protection plans
- Opportunities to join brain health research programmes in Scotland

Our work falls into two main strands. The first is focused on engaging the public with the concept of brain health. We are developing a suite of partnerships to embed positive brain health behaviours in all walks of life – including in nutrition, fitness, stress management and lifelong learning.

One of our first activities is to design educational resources for a variety of audiences from primary schools through to health care professionals so everyone can join the effort to better understand brain health and disease.

We are also working with supermarket and food producers to explore ways of providing clear advice about which foods keep our brains healthy. And we will shortly launch a nationwide survey to understand more about how people in Scotland think about their brain health.

Our other main strand of work will be to collaborate with healthcare partners. We are actively developing Scotland’s first brain health clinics, at which patients will be able to access the information and interventions they need to protect their brain, as well as the Scottish Brain Health Register – a national register of people keen to join research programmes and trials of new treatments.

These Brain Health Services will help to detect and manage the most common brain health problem we face – namely Alzheimer’s disease. Through all our activities, we expect that in future fewer people in Scotland will develop Alzheimer’s disease, but for those who do, we will work to ensure they access the best assessments, treatments and care of anywhere in the world.

Keeping your brain healthy

We now understand a great deal more about what impacts our brain health than we did even ten years ago. For example, it is widely known that the diseases that lead to dementia start in midlife. The onset of these disease is driven by many factors – some of which we can’t change, such as family history and genetics, but many of which we can, such as lifestyle.

If we eat, exercise and sleep well we keep our brains healthy. Clean, unpolluted air is important too, so that our brains have a good supply of oxygen. Nothing stimulates the brain more than being with people we care about, having fun and being as calm as we can be at home and work.

BHS is working to ensure this growing evidence base is applied in healthcare and public health campaigns.

Meet the team

I joined as Executive Lead of BHS in July. Having begun my professional life as a journalist with the Sunday Times and the Scotsman, I have spent most of my career working to engage the public and media with medical research and expertise at the University of Edinburgh. I led communications and fundraising at the Centre for Dementia Prevention,
I am fortunate to be joined in the team by our Director, Professor Craig Ritchie, of the University of Edinburgh. Professor Ritchie is a world-leading authority on brain health and has been a senior investigator on more than 30 drug trials of both disease-modifying and symptomatic agents for dementia. He is the Chair of the Scottish Dementia Research Consortium, Professor of the Psychiatry of Ageing and Director of the Centre for Dementia Prevention at the University of Edinburgh.

Neil Fullerton completes our team and joined us in July as the Project and Communications Lead. Neil has a wealth of experience in managing clinical research studies and supporting research participants, as well as leading public engagement campaigns focused on dementia prevention.

What you can do

There are many ways you can get involved with Brain Health Scotland:

1. Join research – taking part in brain health research is one of the greatest ways to impact future success: [https://www.joindementiaresearch.nihr.ac.uk](https://www.joindementiaresearch.nihr.ac.uk)

2. Learn about brain health – we will shortly be launching a free online learning course, or MOOC – Massive Open Online Course – about Understanding Brain Health.

   If you are keen to learn more, please contact the Brain Health Scotland team or go to [https://www.brainhealth.scot](https://www.brainhealth.scot)

3. Partner with us – we are keen to work with partners from all walks of life, so if you would like to develop a partnership with us, get in touch and we will identify how to embed positive brain health in your area of interest.
Jean Georges looks back on his 24 years as Executive Director of Alzheimer Europe

On 1 November 1996, Jean Georges joined Alzheimer Europe as its first Executive Director. In this interview, he looks back at some of the key achievements of the organisation and its plans for the coming years.

This year marks 30 years of Alzheimer Europe – what are your reflections on this anniversary?

Looking back on the history of Alzheimer Europe, I want to start by paying tribute to the vision of the founders of our European movement: Michael Coote from Ireland, Henk ter Haar from the Netherlands and Franz Baro from Belgium felt that their associations could both learn from other organisations and share their innovative projects and activities with others.

They convinced the representatives of 106 associations from six countries (Belgium, Finland, Ireland, Netherlands, Poland, and Spain) to meet for the first time on 3 September 1990 and to formally launch Alzheimer Europe. At this meeting, they adopted the following statement “Because we are all satisfied that we will benefit from European co-operation, and together can put more pressure on the European Council, Commission, Parliament and other national and supranational organisations, we have decided to form a European Alzheimer organisation.” Co-operation and lobbying European institutions remain important priorities of Alzheimer Europe to this day.

I had the privilege to meet all three of the founding fathers and I was happy to hear how proud they were of the increasing recognition and scope of the association which they created.

Alzheimer Europe’s role has evolved and now looks significantly different to its earlier years – can you tell us more about how and why this change occurred?

I am truly proud to have been able to lead Alzheimer Europe over the past 24 years and accompany and, sometimes, instigate the many changes that the organisation has undergone.

Fundamentally, some of the key roles and priorities of the organisation remain unchanged. Alzheimer Europe is, above all, the umbrella organisation of national Alzheimer’s associations and their support continues to be an important role. The membership of the association has of course grown from the 10 founding organisations from 9 countries to 39 associations from 35 countries.

Similarly, we continue to raise awareness of dementia, represent the interests of people with dementia and their carers and lobby the European institutions for a greater recognition of dementia as a public health priority. However, the importance given to these priorities has changed considerably.

At the beginning of Alzheimer Europe, the focus was predominantly on supporting national members, helping them setting up websites and providing them with material, such as the Care manual or the Children’s book, which could help them in providing advice to carers and much needed information on Alzheimer’s disease.

As the member associations continued to grow themselves and as the awareness of Alzheimer’s disease increased, Alzheimer Europe started to focus more on its policy work and in 2006, we adopted our Paris Declaration with the political priorities of the European dementia movement. This was followed by the development of our European
Alzheimer’s Alliance with Members of the European Parliament and the recent creation of our European Group of Governmental Experts on Dementia with representatives of national health ministries.

Another key change for the organisation was the inclusion and involvement of people with dementia. Alzheimer Europe and most of our member organisations were set up and run by carers of people with dementia. Over the years, the diagnosis of Alzheimer’s disease and other types of dementia was being made at an earlier stage. As more people with dementia were able to speak out and advocate for their own needs, Alzheimer Europe responded by identifying ways in which their views could be included in the projects and the governance of the association. With the creation of the European Working Group of People with Dementia in 2012, Alzheimer Europe was able to ensure that the voice of people with dementia is heard in all our activities and projects. The Chair of the group also sits on the Board of Alzheimer Europe with full voting rights and we have benefited hugely from the input and advice of the chairpersons to date, Helga Rohra from Germany and Helen Rochford-Brennan from Ireland, but equally from all the members of the European Working Group.

A final and more recent change has been the involvement of Alzheimer Europe in research. From 2006 to 2008, Alzheimer Europe coordinated the EuroCoDe (European Collaboration on Dementia) project which was funded by the EU health programme and which resulted in reports and recommendations on the prevalence, treatment, prevention and psychosocial support of dementia in Europe, as well as an overview and comparison of social support systems. In turn, this led to the very close collaboration with INTERDEM, our sister organisation of researchers involved in psychosocial research. Even more recently, Alzheimer Europe has started to partner with EU research projects funded by Horizon2020, the Innovative Medicines Initiative (IMI) and the Joint Programme for Neurodegenerative Diseases Research (JPND) where we contribute to and sometimes lead the dissemination, ethics and patient and public involvement activities.

“Over the years, Alzheimer Europe has become a recognised and valued partner at a European level in the advocacy and research worlds. I am particularly proud of how we have been able to adapt and change.”
What achievements are you most proud of during your time as Executive Director?

Over the years, Alzheimer Europe has become a recognised and valued partner at a European level in the advocacy and research worlds. I am particularly proud of how we have been able to adapt and change as mentioned above.

When it comes to the involvement of people with dementia, Alzheimer Europe was able to be a pioneer and I am really delighted to see how many of our national member organisations have followed our example of setting up working groups of people with dementia to advise the associations and help them in their advocacy work towards national policy makers and governments. It has been a real privilege to work alongside and with the members of our European Working Group of People with Dementia who truly transformed the way in which our organisation operates.

I am also proud of how Alzheimer Europe has been able to make dementia a European priority thanks to coordinated campaigns at European level and, together with its members, at national level. When we adopted the Paris Declaration in 2006, only France had a very modest national Alzheimer’s plan. Over the years though, the number of countries with national dementia strategies has increased significantly.

What have been the biggest challenges for the organisation and how have these been overcome?

The ongoing COVID-19 pandemic is undoubtedly one of the biggest challenges which Alzheimer Europe and our national member organisations have had to face. I have truly been in awe at how national organisations have risen to the challenge and adapted their services to the new situation. They have provided counselling and support via teleconferences, used new technologies to connect people with dementia with each other and with their families, provided information on the pandemic in easy to understand language specifically targeted at people with dementia, adapted routines in day care and nursing homes to protect residents and clients and continued their lobbying towards national governments to ensure that dementia remains a priority despite the ongoing pandemic. Alzheimer Europe was able to support these developments by developing a COVID-19 resource centre on the website and organising meetings with national health ministry officials and with members to allow an exchange of information and good practices.

The organisation will soon set out its five year strategic plan – what can we expect the future focus of the organisation to be?

For the coming years, I do not see a revolution, but rather an evolution of the five strategic priorities, as I believe we will need to continue to give a voice to people with dementia, make dementia a European priority, promote a human-rights based approach to dementia, support research and strengthen the European Dementia Movement. I look forward to continuing to lead Alzheimer Europe in advancing these aims.

“ I am also proud of how Alzheimer Europe has been able to make dementia a European priority thanks to coordinated campaigns at European level and, together with its members, at national level.”

“The ongoing COVID-19 pandemic is undoubtedly one of the biggest challenges which Alzheimer Europe and our national member organisations have had to face.”
Iva Holmerová shares some of her highlights as Chairperson of Alzheimer Europe

Iva Holmerová from the Czech Alzheimer’s Society was elected as Chairperson of Alzheimer Europe at the 2016 Annual General Meeting of the organisation in Copenhagen. Before that, she was a Vice-Chairperson (2010–2016) and member of the Alzheimer Europe Board (2008–2010). In this interview, she shares some of her highlights.

This year marks 30 years of Alzheimer Europe – what are your reflections on this anniversary?

I remember Alzheimer Europe from its early and modest beginnings and it is really great to see how much we have achieved.

This has been a great collaborative effort, which would not have been possible without the incredible efforts of our national member organisations and their representatives who contributed to our meetings, projects and activities over the last years. I was also incredibly lucky with my fellow Board members who supported me in my work and provided good governance, strategic advice and efficient monitoring of Alzheimer Europe’s activities and finances.

Last but not least, I want to single out the skilled and enthusiastic work of our staff in Luxembourg under the leadership and guidance of our Executive Director, Jean Georges.

The membership and activities of Alzheimer Europe have grown significantly during your time as a Board member and Chairperson of Alzheimer Europe. How did you deal with this growth and expansion in the Board?

To some extent, the Board has functioned in a very similar way over the past years. We meet four times a year and our meetings are combined with our European lunch debates, company round tables with our corporate sponsors and meetings with our national member organisations. These are intensive days, but it is a great way of combining and concentrating our efforts.

I have tried to follow the example of my predecessors Heike von Lützau-Hohlbein from Germany and Maurice O’Connell who had both been able to promote very open exchanges between Board members where everyone’s voice is included and heard. I really enjoy the very friendly, constructive and fair collaboration in the Board and with all member organisations.

With the creation of our European Working Group of People with Dementia, we now have the chairperson of the group attending as a full member. We have had great representatives with Helga Rohra from Germany and Helen Rochford-Brennan from Ireland making sure that we properly represent and include people with dementia in all our efforts and projects.

According to you, what have been the most important areas of work in which Alzheimer Europe has been involved?

It is not possible to mention all of them. I think that it is very important that we are able to meet with all our member organisations several times during the year to exchange our experiences and support each other. It is incredibly rewarding to chair these meetings and to see how generously member organisations are sharing their great innovative projects with others. These meetings are incredibly enriching and participants leave with new ideas for their own organisations and countries. As a representative from the Czech Republic, I am particularly proud of how Alzheimer Europe has managed to involve representatives of our member organisations from Central and Eastern Europe. Finally, people with dementia play a very important role in our organisation and I feel that Alzheimer Europe can be a model for other organisations on how to conduct and promote patient and public involvement activities.

What do you see as the future priorities for Alzheimer Europe?

The ongoing COVID-19 pandemic has fundamentally changed how Alzheimer Europe and our national member organisations function, meet and exchange information. Thankfully, it has also contributed to a growing recognition of European policy makers that public health and prevention need to feature more prominently on the European agenda.

Together with our members, we need to continue in our efforts to make sure dementia is not forgotten as a priority in Europe or in our respective countries. I look forward to my continued involvement in Alzheimer Europe to help respond to arising challenges and support our member organisations.
Alzheimer Europe’s Honorary Treasurer reflects on the financial history of the organisation

Alzheimer Europe’s financial position has evolved considerably over its 30 year lifetime and the role of the Honorary Treasurer has been key in overseeing the organisation’s finances. As such, we spoke to the outgoing Honorary Treasurer, Maria do Rosário Zincke dos Reis, about her experiences working on the Alzheimer Europe Board and her outlook on the financial position of Alzheimer Europe.

This year marks 30 years of Alzheimer Europe – what are your reflections on this anniversary?

I joined Alzheimer Portugal in 2000. At that time Alzheimer Portugal was already an Alzheimer Europe member and I remember hearing a lot about our participation in the Lawnet 1 that had come to an end the year before.

I will never forget the 2004 Annual General Meeting, in Prague. There, Alzheimer Portugal’s application to host the 17th Alzheimer Europe Conference was approved. The conference, entitled “The Sound of Silence”, took place in May 2007 at Estoril, Portugal.

Additionally, I will never forget the enthusiasm and pride I felt for belonging to the European Dementia Movement when the national organisations unanimously signed the Paris Declaration in 2006.

From those distant days I have no memories about finances. But visiting the 1999 Annual Report Preface, written by then-Chairperson Jeannot Krecké, I read this interesting statement: “Yet despite the growing recognition and ever expanding activities of our organisation, I cannot end this Annual Report without raising the thorny issue of the financial situation of Alzheimer Europe. The significant budget deficit and the shrinking reserves of the organisation force the organisation to reconsider its financial strategy and to develop new avenues to diversify its sources for funding.”

During your time as a member of the Alzheimer Europe Board and as Honorary Treasurer, how has Alzheimer Europe’s financial position evolved over the years?

I have been a Board member of Alzheimer Europe since 2008 and was elected as Honorary Treasurer in 2010. Since then, of course not because of me, Alzheimer Europe never stopped growing not only in public recognition but also in financial sustainability. Indeed it is the way Alzheimer Europe has been able to define its priorities, long term plans and strategies and also its high quality performance in all the projects in which it has been involved in that allow the current very healthy financial situation.

From a budget of 1,188,870 in 2010 we reached a budget of 1,890,058 in 2019. The Alzheimer Europe accounts are a reflection of its attitude, which is characterised by:

- Precaution – never take a step longer than the leg
- Keeping the focus – being able to listen to the voice of people with dementia and promote their involvement in society and in the life of the organisation, namely having a voice in relation to research
- Flexibility – embrace new challenges such as involvement in a growing number of increasingly demanding European projects, requiring a higher level of skill.

What have been the most significant developments in relation to the finances of the organisation?

2010 was a particularly successful year as, for the first time, the organisation’s budget exceeded EUR 1 million. It was also the year where we received a grant from Bayer for our Value of Knowing project which received critical acclaim for our survey on the perceptions of the general public in five countries regarding Alzheimer’s disease and its attitudes towards the importance of timely diagnosis. In 2012, Alzheimer Europe was able to set up its own Foundation which aims to support the involvement of people with dementia in our activities, projects and meetings. Since then, the Alzheimer Europe Foundation has supported people with dementia in attending Conferences and has given awards to conference posters promoting a positive image of dementia.

The growing percentage of EU subsidies in our income are very meaningful giving us a
high responsibility to keep the confidence of European institutions in Alzheimer Europe.

What will be the priorities in the years ahead to strengthen the financial position of Alzheimer Europe?

In these times of uncertainty it is especially important to preserve our role leading the European Dementia Movement and keeping the recognition from the European Commission and other European institutions. The diversity of funding sources is also something to always keep in mind.

As the Honorary Treasurer of Alzheimer Europe during the last 10 years I am confident that we will be able to face the coming challenges as we did before.

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Our work at Eisai prioritises patients and their families through our focus to continually improve the benefits that healthcare can provide.

We call this *human health care (hhc)*.

About Eisai

Eisai is a leading global research and development-based pharmaceutical company headquartered in Japan. We define our corporate mission as ‘giving first thought to patients and their families and to increasing the benefits health care provides’, which we call our human health care philosophy. With over 10,000 employees working across our global network of R&D facilities, manufacturing sites and marketing subsidiaries, we strive to realise our human health care philosophy by delivering innovative products in various therapeutic areas with high unmet medical needs, including oncology and neurology.

As a global pharmaceutical company, our mission extends to patients around the world through our investment and participation in partnership-based initiatives to improve access to medicines in developing and emerging countries.

For more information about Eisai in EMEA please visit www.eisai.eu.

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Looking back at 30 Years of Alzheimer Europe shaping dementia policy in Europe

On 3 September 1990, representatives of six national associations came together for the first time in Leuven, Belgium, marking the beginning of Alzheimer Europe (AE) as the Europe-wide organisation for dementia. In this article, we look at some of the major firsts that Alzheimer Europe has pioneered to help shape the policy agenda at a European level over the past 30 years.

“Because we are all satisfied that we will benefit from European co-operation, and together can put more pressure on the European Council, Commission, Parliament and other national and supranational organisations, we have decided to form a European Alzheimer organisation”.

With this statement, Franz Baro (Belgium), Michael Coote (Ireland), Tomasz Gabryelewicz (Poland), Henk ter Haar (Netherlands), Maria Jacobs (Belgium), Leila Mustanoja (Finland), Jo van der Poel (Netherlands), Micheline Selmes (Spain) and Miet Wouters (Belgium), set the foundations for the establishment of Alzheimer Europe.

Below, we take a look, in chronological order, at some of the “firsts” in Alzheimer Europe’s history, which have helped set the basis of the work of the organisation and helped to shape dementia policy at a European level.

AGM and Executive Committee

On 19–20 January in Noordbergum, Netherlands, the creation of Alzheimer Europe is confirmed and the founding members are the Alzheimer associations from Belgium, Finland, France, Germany, Ireland, the Netherlands, Poland, Spain and the UK (Alzheimer’s Society and Alzheimer Scotland).

An Executive Committee is elected, consisting of Michael Coote (Ireland) as Chairperson, Henk ter Haar (Netherlands) as Treasurer and Franz Baro (Belgium). The first Statutes of the organisation are approved at the Annual General Meeting of the organisation in Amsterdam on 22 September. Alzheimer associations from Denmark, Italy, Sweden and Switzerland join the growing family of AE members.
The Alzheimer Europe Newsletter

1991

The first AE newsletter was produced for the first AE AGM in Amsterdam in 1991, with 1,000 paper copies distributed to the participants.

The focus of the newsletter has broadened considerably since its initial inception, seeking to act as a key source of information for all developments relevant to dementia in Europe.

This includes across the spheres of policy, science and research. Additionally, we are able to share the good practice and excellent work of our members at a national level.

Today our newsletter is fully digital and is sent to over 8,000 people every month.

Recognition of Alzheimer Europe

1996

In 1996, the European Parliament adopted a report on Alzheimer’s disease which recognised Alzheimer Europe as the umbrella organisation for Alzheimer’s associations. This recognition both strengthened the role of Alzheimer Europe in its push to prioritise dementia at a European level and as an organisation which added value to the development of policy and practice.

Similar recognition and accreditation has since followed, with Alzheimer Europe being recognised by the Council of Europe (1999), the European Medicines Agency (2006) and the World Health Organization – European Region (2018).

The Alzheimer Europe Website

1997

Alzheimer Europe launched its first website in 1997, uploading resources and materials from members and that it had produced itself.

Today our website hosts all of Alzheimer Europe’s publications, newsletters, news stories, position statements, as well as information about the organisation, its membership and governance information. An average of 58,000 people visit our website each month, from almost 200 countries and nations across the world.
Paris Declaration

A century after Alois Alzheimer first described the symptoms of the disease that was to bear his name, Alzheimer Europe and its member organisations formally adopted a Declaration on the political priorities of the European Alzheimer Movement at the AE Conference in Paris in the summer of 2006.

The Declaration called upon policy makers at an international, European and national level to prioritise Alzheimer’s disease and other forms of dementia.

This marked a significant shift in Alzheimer Europe’s approach to making dementia a political priority, laying the foundations for the future of Alzheimer Europe’s policy and engagement work, including the 2014 Glasgow Declaration.

European Collaboration on Dementia – EuroCoDe

The first major European dementia project of its kind, the European Collaboration on Dementia (EuroCoDe) aimed to develop a European network of all stakeholders from different disciplines to jointly develop consensual indicators and establish an ongoing dialogue on major issues on dementia, specifically:

- Consensual prevalence rates
- Guidelines on diagnosis and treatment
- Guidelines on non-pharmacological interventions
- Risk factors and risk reduction and prevention strategies
- Socio-economic cost of Alzheimer’s disease
- Inventory of social support systems

The programme ran from 2006–2008 and was jointly funded by the European Commission and the Fondation Médéric Alzheimer. This work has continued to influence and inform many key areas of work, including Alzheimer Europe’s Dementia in Europe 2019 on dementia prevalence.
Alzheimer Europe Survey – Who Cares?  

In 2006, Alzheimer Europe worked with H. Lundbeck A.S., as well as its member organisations in France, Germany, Poland, Spain and Scotland, which was completed by 1181 informal carers of people with dementia across these five countries. The result demonstrated the challenges and difficulties faced by informal carers, in relation to the people with dementia, including the extent of individual’s caring responsibilities and the lack of adequate support and the high costs of services. This survey was the first of its kind conducted by Alzheimer Europe (published in its own right and not as part of another project) and this exercise was subsequently repeated in 2011 and 2016.

European Parliament Lunch Debate  

In November 2006, on the occasion of the centenary of Alois Alzheimer’s discovery of the disease, Alzheimer Europe organised a lunch debate in the European Parliament in Brussels. Hosted by Astrid Lulling (Luxembourg), over 20 participants from different European institutions and 12 Members of the European Parliament attended. At the meeting, the findings of the first Dementia in Europe Yearbook were presented to attendees, alongside the formal launch of the Paris Declaration.

Dementia in Europe Yearbook  

In November 2006, Alzheimer Europe for the first time published its Dementia in Europe Yearbook. The first edition of this publication provided an overview of the prevalence of dementia, the reimbursement systems for anti-dementia drugs and the provision of home care, as well as a detailed description of findings for 31 European countries. Alzheimer Europe has published annual Yearbooks ever since, with a different thematic focus each year including the prevalence of dementia in Europe, national dementia strategies and residential care standards.

These reports are also shared with members, policy and decision makers, academics and industry partners across Europe, to inform policy and decision-making.
In November 2006, Alzheimer Europe published the first of its reports dedicated to ethical issues in dementia. The first edition of these reports contains Alzheimer Europe’s position on advance directives and provides background information on the legal, ethical, medical and personal as well as practical issues surrounding the use of advance directives for people with dementia. This is followed by a summary of the legal status of advance directives in 15 EU member states and in Switzerland and Norway.

Alzheimer Europe has published ethics reports on an annual basis ever since, focused on ethical issues within a certain area of dementia policy or practice, with a different theme explored each year. These reports are sometimes also translated into French and German. As with the Yearbook, these report are shared with members, policy and decision makers, academics and industry partners across Europe, to inform policies and practice.

In September 2007, 27 Members of the European Parliament from 16 European countries came together to establish the European Alzheimer’s Alliance (EAA), with Françoise Grossetête (France), serving as its first Chairperson. The EAA is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament to support Alzheimer Europe and its members in making dementia a public health priority in Europe. Its primary mission is to:

- Send out the political message that concerted action is needed in the field of prevention, diagnosis and treatment of Alzheimer’s disease, as well as research and social policies.
- Promote actions to give dementia priority at European and national level.

Today the EAA has 95 members from 26 Member States, with Sirpa Pentikäinen MEP (Finland) serving as Chairperson.
The Dementia in Europe magazine was launched in June 2008 as a way of raising and maintaining both awareness and interest in dementia issues, as well as providing up-to-date information on the most relevant developments, both at a European and national level.

The first edition brought together articles on the most recent findings regarding factors which may increase and/or decrease the risk of developing dementia, which were presented during the third lunch debate at the European Parliament, as well as France’s pledge to invest EUR 1.6 billion on dementia and proposals for an English Dementia Strategy. Since then the magazine has been published three times per year, with an overhaul of the magazine’s layout taking place in June 2018, marking the 10th anniversary of the magazine’s launch.

When the magazine was first published in 2008, it was sent to 2,327 number of people. Today the magazine has a reach of over 11,000 people!
ALCOVE – Joint Action on Dementia

For the first time, the European Commission funded a Joint Action focused on dementia bringing together 30 partners from 19 EU Member States. This Joint Action, Alzheimer COoperative Valuation in Europe (ALCOVE), ran from 2011–2013 and aimed to improve knowledge and to promote the exchange of information on dementia in order to preserve the health, quality of life, autonomy, and dignity of people living with dementia and their carers in EU Member States.

The ALCOVE project had four key work packages aimed at different aspects of dementia. These were:
- Epidemiological data on dementia
- Timely diagnosis of dementia
- Rights, autonomy and dignity of people living with dementia
- Support systems for behavioural and psychological symptoms of dementia.

Following the completion of this project, a second European Joint Action on Dementia, the Act on Dementia project, was established and ran from 2016–2019.

European Working Group of People with Dementia (EWGPWD)

In April 2012, in Glasgow, Scotland, the first meeting of the European Working Group of People with Dementia was held, bringing together people with dementia from Czech Republic, England, Germany, Ireland, the Netherlands and Scotland.

The group 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. The group operates independently, with members electing their own Board and setting an agenda of activities. The Chairperson is also an ex-officio member on the Board of Alzheimer Europe with full voting rights.
In June 2017, Alzheimer Europe published its first Dementia Monitor publication, which aimed to provide a benchmark of national dementia policies in order to compare the responses of European countries to the dementia challenge in different domains.

Information was collated from a survey of our national member organisations, as well as a number of online sources, in an effort to create a tool for national organisations to compare their situation to that of other European countries. In doing so, Alzheimer Europe, as a European organisation, was also better able to understand the differences that exist between countries and what areas should be prioritised. The next edition of the Monitor will be published at the end of 2020.

The European Group of Government Experts met for the first time on 3–4 December 2018, bringing together government-nominated representatives from across Europe to discuss progress and developments in relation to dementia policy, practice and research. The meeting was facilitated by Alzheimer Europe, the Dutch Ministry of Health, Welfare and Sport, the Italian Ministry of Health and the Scottish Government, as they had agreed that losing the European Commission Expert Group would be detrimental, as no other platform existed in which governments exchange knowledge and information.

In total, 17 governments attended the first meeting of the group, with a further six expressing an interest in participating. Also in attendance as observers were representatives from Alzheimer Europe, the European Commission, the Organisation for Economic Cooperation and Development (OECD) and the World Health Organisation (WHO). The group continues to meet every six months, most recently having met online due to the COVID-19 pandemic.
Our members are helping people with dementia and their carers in 35 countries
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