Marian Harkin, MEP hosts Alzheimer Europe lunch debate on dementia as a priority of the EU health programme.

Marian Harkin

José Luis Molinuevo delivers the keynote lecture at the 28th Alzheimer Europe Conference.

Helga Rohra looks back on six years with the EWGPWD.

Marianne Thyssen discusses developments in social affairs at an EU level.
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I am pleased to welcome you to the 29th edition of our Dementia in Europe magazine.

The first section highlights some of our efforts to ensure dementia remains a European priority, including our recent lunch debate in the European Parliament, which focused on dementia as a priority of the EU health programme. During the debate, Geoff Huggins, Director of Health and Social Care Integration at the Scottish Government presented the work of the second European Joint Action on dementia and Jean Georges, Executive Director of Alzheimer Europe, gave an overview of some of the work taking place at a European level, including some of the policy and legislative drivers from the European Union. Additionally, he highlighted some aspects of Alzheimer Europe’s work, including our annual publications, the 2018 editions of which are also presented in this first section.

With the upcoming European elections (May 2019), we decided to ask MEPs in the European Parliament, which their views and plans for the future of the EU. Readers can also find out what is happening with the European Accessibility Act and the Work-Life Balance provisions associated with the European Social Pillar in two further articles. For the latter, we spoke to Commissioner for Employment, Skills, Social Affairs and Labour Mobility, Marianne Thyssen.

Also at European level, representatives of the Innovative Medicines Initiative (IMI), which celebrated its 10th anniversary in 2018, spoke to us about some achievements to date and about Alzheimer Europe’s involvement in IMI projects.

Finally, on the national policy front, we have heartening news from Germany, where the Federal Government has announced its intention to develop a national dementia strategy.

At national level, we look at work being done in three countries: Belgium, France and Germany.

In Germany, the INTERREG-Danube INDEED project is developing an intervention to support occupational collaboration in order to improve care for people with dementia in the Danube region, Project Coordinator Alexander Kurz and Project Manager Lea Pfäffel tell us more.

The Flemish Region of Belgium has its first-ever working group of people with dementia. Olivier Constant from the Flanders Centre of Expertise on Dementia and Hilde Lamers of the Alzheimer’s League Flanders introduce the group. Providing a voice to people with dementia and their carers is an important part of what we do and groups like this are of paramount importance to ensure their voices are heard.

In France, an overwhelming majority of the public disagreed with the government’s decision to stop reimbursing anti-dementia drugs. France Alzheimer tried hard to have this decision reversed, via a campaign, supported by Alzheimer Europe, and a national survey, conducted together with the Société Française de Neurologie (SFN) and the Fondation pour la recherche sur Alzheimer. We asked Prof. Bruno Dubois to tell us more about the results of the survey and the impact of this controversial government decision.

Finally, we take a look “behind the headlines”, with Prof. Craig Ritchie and Dr Samuel Danso, both from the University of Edinburgh, who comment on recent headlines about Artificial Intelligence (AI) and its ability to predict Alzheimer’s.

Our “special section” takes a look back at the success of our 28th Alzheimer Europe Conference held in Barcelona. Key presentations at the opening ceremony and the plenary sessions are covered and we also showcase the contributions of people with dementia at the conference.

Happy reading!
European Parliament lunch debate focuses on dementia as a priority of the EU health programme

Alzheimer Europe and the European Alzheimer’s Alliance organised a lunch debate in the European Parliament, hosted by Marian Harkin, MEP.

Alzheimer Europe held its final lunch debate of 2018 in the European Parliament on 4 December 2018, which focused on the topic of “Dementia as a priority of the EU health programme”.

Hosted by European Alzheimer’s Alliance member Marian Harkin, MEP (Ireland), the debate was well attended with 92 delegates from across Europe, comprising representatives from the European Working Group of People with Dementia (EWGPWD), national Alzheimer’s Associations, national government representatives, research partners and pharmaceutical representatives.

Welcoming delegates and opening the session, Marian Harkin MEP (Ireland) noted that a recent report from the Organisation of Economic Coordination and Development (OECD) had estimated that around 9 million people were living with dementia in EU Member States. Ms Harkin noted that with no cure currently available, better policies and interventions were key to improving the lives of people with dementia. However, she also noted some of the difficulties in achieving European action, noting that the Council was very clear about health remaining a Member State competence.

Geoff Huggins, Director of Health and Social Care Integration at the Scottish Government presented on the work of the second European Joint Action on dementia, “Act on Dementia”. Mr Huggins explained that the project was an example of an EU project funded from the health programme, building on ALCOVE, the previous Joint Action.

He explained to delegates that unlike other projects, which often focus on generating new knowledge or information, the previous project had shown that the information was available but was not being translated into practice. As such, the focus of the second Joint Action was to demonstrate how good practice could be embedded and spread within different countries, with their different contexts and health structures.

“Iva Holmerová

“Europe is changing. Families are more international. By sharing good practices and knowledge, dementia could be a flagship area, positively influencing lives through collaboration.”

“Deeds, not words, are what we need now across Europe to improve the lives of people with dementia and their carers.”

Geoff Huggins
Beginning in 2016 and due to run for three years, the programme has involved more than 10 countries, with additional collaborators and partners supporting the work, including Alzheimer Europe. Mr Huggins outlined the project focused on identifying best practice for people with dementia within four work packages:

- Diagnosis and post-diagnostic support – led by France
- Crisis and care coordination – led by Italy and The Netherlands
- Residential care – led by Norway

Mr Huggins also explained to delegates that workstreams on coordination and dissemination are both being led by the Scottish Government, with the Agency for Health Quality and Assessment of Catalonia (AQuAS) in Catalonia leading the evaluation of the project.

The project is due to conclude and report on its work in October 2019.

**European-level policies and Alzheimer Europe workstreams**

Jean Georges, Executive Director of Alzheimer Europe presented to delegates on some of the relevant work taking place at a European level, taking the opportunity to reflect on the progress made to date, some outstanding challenges and concerns, and identifying what Alzheimer Europe would like to see take place next.

Mr Georges set out the context around the work to establish dementia as a European priority, highlighting that the Paris Declaration in 2006 was a catalyst for the beginning of a political movement, calling for additional funding for research, as well as a more coordinated and holistic approach to research. He further explained that activities beginning under the French Presidency in 2006 had been incredibly helpful in establishing dementia as a priority.

In the following years, there was significant progress made in relation to increases in EU funded dementia research, through a number of different programmes, including the 7th and 8th Framework Programmes for Research and Technological Development (FP7 and Horizon 2020), the Joint Programme on Neurodegenerative Diseases (JPND) and the Innovative Medicines Initiatives (IMI) 1&2.

More recent policy and legislative drivers from the European Union have included the European Social Pillar and the Work-Life Balance initiative, which aim to improve the lives of people with dementia and their carers. At a national level, Mr Georges noted that both the Swedish and German governments had recently committed to developing national dementia strategies, whilst Portugal published a strategy in the summer of 2018.

Focusing on the contribution of Alzheimer Europe, Jean Georges explained that Alzheimer Europe had 42 member organisations from 37 countries, with Estonia and FYR Macedonia, having joined in October 2018. He noted that the EU Health Programme allowed Alzheimer Europe to carry out much of its work, including its yearbooks and ethics publications, information dissemination through
its newsletter and website, and capacity building amongst member organisations. The organisation also supported the European Alzheimer’s Alliance, which contained 126 MEPs from 27 EU Member States.

Alzheimer Europe had also been in a position, working with the Dutch, Italian and Scottish governments, to support a new Governmental Expert Group on Dementia, following the European Commission’s decision to disband its dementia expert group.

Jean Georges concluded his presentation by sharing Alzheimer Europe’s campaign pledge for the European Parliament Elections in May 2019. Alzheimer Europe and its members will be asking candidates standing for election to sign the European Dementia Pledge, committing them to joining the European Alzheimer’s Alliance and working to make dementia a European priority.

Open floor discussion

Following the presentations, there was an open floor discussion involving delegates, with questions posed for the presenters on future areas of focus, as well as contributions from people living with dementia and carers of people with dementia who shared their experiences of living with the condition.

Helen Rochford-Brennan, Chair of the European Working Group of People with Dementia (EWGPWD) enquired why social care had not been included as a focus of the work of the Joint Action. Mr Huggins responded that partners had a limited scope of areas which they could examine but that this was something which may be examined in future by the Governmental Expert Group.

Nélida Aguiar, carer for her mother, Idalina – a member of the EWGPWD – highlighted her experience on Madeira (Portugal), working to ensure carers received support and asked how we can ensure national governments make this support available for everyone. Jean Georges agreed that this was challenging and said that even in developed countries, it was an area which was often not given enough attention.

Nessa Childers, MEP (Ireland) asked about continuing this work into the next parliament and Mr Georges highlighted that, in the run up to the elections, Alzheimer Europe, together with its members, would let candidates know how they can be involved and the key issues for the dementia agenda.

Deirdre Clune, MEP (Ireland) asked whether or not enough was being spent on social aspects of dementia, including in relation to research, noting that there is a lot we can do that makes a difference quite quickly. Mr Georges agreed noting this was the basis of the “care today, cure tomorrow” approach Alzheimer Europe advocated.

Carmel Geoghegan, supporter of Helen Rochford-Brennan, asked about GP buy-in. Geoff Huggins noted that as part of the Joint Action’s work in France and Italy, variable buy-in was evident and that finding out what practitioners found useful was crucial.

At the end of the meeting, Iva Holmerová, Chair of Alzheimer Europe, presented Helga Rohra with a plaque thanking her for six years of service in the EWGPWD, including four years served as the group’s first Chair. You can read our interview with Helga on page 28.

Alzheimer Europe’s next European Parliament lunch debate is taking place on 26 February 2019, focusing on “Dementia as a European research priority”.

According to Alzheimer Europe, 8.7 million Europeans live with dementia and these numbers are expected to at least double by 2050. Dementia deserves to remain a priority of future EU health and research programmes!”

Jean Georges
Alzheimer Europe AGM elects new Board and welcomes two new member organisations

On 29 October 2018, Alzheimer Europe held its Annual General Meeting (AGM) in Barcelona. Member associations elected a new Board which will serve until 2020 and accepted two new provisional member organisations.

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 belong to full member organisations of Alzheimer Europe.

Iva Holmerová (Czech Republic) – Chairperson
Iva is founder of the Czech Alzheimer Society, holds a PhD in Social Gerontology and is a practicing physician qualified in General and Geriatric Medicine. Iva is also the Director of the Czech Centre of Gerontology and joined the Board of Alzheimer Europe in 2008, serving as Vice-Chairperson from 2010 to 2016 until she became Chairperson in 2016:

“I have been involved in the dementia movement for many years, during which my ‘purely’ professional view on dementia has changed, due to meetings with people with dementia and caregivers and to my close personal insights. As Chairperson, I would encourage all countries in the European region to join our membership and to be as active as possible. Some of the issues faced by people with dementia require international collaboration.”

Charles Scerri (Malta) – Vice-Chairperson
Charles is a graduate 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 has been Vice-Chair of Alzheimer Europe since October 2016. Prior to this, he was Alzheimer Europe’s Honorary Secretary:

“For years, Alzheimer Europe has been advocating to make dementia a health and social priority in European countries. As Vice-Chair, I have gained significant experience in the workings of dementia associations throughout Europe, which in turn was instrumental in finding ways in which we can come together for the benefit of individuals with dementia, their caregivers and family members.”

Jim Pearson (UK – Scotland) – Honorary Secretary
Jim is Alzheimer Scotland’s Director of Policy & Research and is responsible for Alzheimer Scotland’s public policy 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. Jim has an MBA from Glasgow Caledonian University and joined the Board of Alzheimer Europe in 2014:

“My experience as member of Alzheimer Europe’s Board has been very rewarding personally and as a representative of a national organisation, because it has allowed me to learn a lot from my colleagues and keep up with what is happening across Europe in the field of dementia. The opportunity to participate in decisions and in defining Alzheimer Europe’s strategy has been of great importance to me and to Alzheimer Portugal, where I can share initiatives and achievements.”

Maria do Rosário Zincke dos Reis (Portugal) – Honorary Treasurer
Rosário has been practicing law in Portugal since 1987, focussing on family law and the legal rights of people with incapacity. She joined the Alzheimer Europe Board in 2008, and became Honorary Treasurer in 2010. She is heavily involved in Alzheimer Portugal, as a current Board member and trainer on Legal and Fundamental Rights of elderly people and people with incapacity:

“My experience as member of Alzheimer Europe’s Board has been very rewarding personally and as a representative of a national organisation, because it has allowed me to learn a lot from my colleagues and keep up with what is happening across Europe in the field of dementia. The opportunity to participate in decisions and in defining Alzheimer Europe’s strategy has been of great importance to me and to Alzheimer Portugal, where I can share initiatives and achievements.”

Helen Rochford-Brennan (Ireland) – Chair of the EWGPWD
Helen was the Vice-Chairperson of the EWGPWD from 2014–2016 and became the group’s Chairperson, thus also joining the Board of Alzheimer Europe, in October 2016. She is on
the Monitoring Committee of Ireland’s first National Dementia Strategy and is a Global Dementia Ambassador.

A life-long Rights and Social Justice Campaigner, Helen now advocates for the rights of people with dementia and was recently awarded an Honorary Doctor of Laws degree from the National University of Ireland Galway.

Helen was diagnosed with Early Onset Alzheimer’s at the age of 62 and has since written very personally about living with Alzheimer’s dementia:

“I am not alone in realising the contribution people with dementia can make. It is great to be part of the ‘Normal Majority’ and not just a person with Alzheimer’s or tokenistic. It gives me a sense of purpose and is an opportunity for me to create awareness of the aspirations and needs of people with dementia to be fully integrated in society. In the words of Ed Roberts “when others speak for you, you lose”. I have a voice of my own. I use that voice at Board meetings to express our needs and aspirations.”

Stefanie Becker (Switzerland)

Stefanie is the Director of Alzheimer Switzerland. A trained psychologist and gerontologist, she holds a PhD in Psychology from Karl-Ruprechts University of Heidelberg, Germany. For almost 20 years, she has been working on the question of stabilising and promoting quality of life for people with dementia. She is also founder and chief editor of the bilingual (German-French) journal Applied Gerontology.

Stefanie joined the Board in 2016:

“Advocating for and supporting the needs of people with dementia and their relatives on the European level is a great opportunity to raise our voice. A voice which only gets stronger and louder with the member organisations. Additionally, the exchange of experience, successful projects or even failures of initiatives between countries is always of mutual importance and inspiring.”

Marco Blom (Netherlands) – New member

Marco graduated from the 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 worked in several positions and was interim CEO from February 2017 until September 2018. Currently he is scientific director and also head of National Services. He is an expert in the field of dementia and has a special interest in scientific research into dementia and development of internet-based interventions for family carers of people with dementia. He is also a Board member of the national Delta Plan Dementia in the Netherlands and editor of Denkbeeld - a Dutch journal on dementia care:

“Since I started to work for Alzheimer Nederland, I much enjoyed the conferences of Alzheimer Europe as a major contribution to strengthen the national organisations in the different countries. I am very motivated to make a good contribution to the work of Alzheimer Europe, with my broad experience in the field of dementia and especially the broad range of activities I am involved in with Alzheimer Nederland. As one of the founding members of Alzheimer Europe, Alzheimer Nederland will actively support the exchange of ideas and experiences (like the Alzheimer Cafés and our online platform for family carers) between member organisations”

Sabine Jansen (Germany)

Sabine is the Executive Director of the German Alzheimer’s association, Deutsche Alzheimer Gesellschaft (DAIzG), the umbrella organisation of more than 130 regional and local Alzheimer associations. Before joining DAIzG in 1995, Sabine completed her studies in social work and worked in various fields of the health sector. She is a member of several advisory boards, including the Ministry of Health and various research projects.

Sabine joined the Board in 2016:

“The work we do at European level is important, not only where health policy issues are concerned, but also in the exchange of experience and knowledge.”

Pat McLoughlin (Ireland) – New member

Pat worked in consultancy prior to becoming CEO of the Alzheimer Society of Ireland in 2016. He 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:

“I hope to help the Alzheimer Europe Board develop strategies to ensure the lived experiences of those with dementia and their carers are central in lobbying the European Parliament.”

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 a substitute member of the Environment, Public Health and Food Safety Committee, as well as the Women’s Rights and Gender Equality Committee:

With a keen interest in working on health issues with various organisations, Ms Pietikäinen joined the Alzheimer Europe Board in 2010.

“Over 10 million people in Europe live with a memory disabling disease, and the number is still increasing. People with memory disabling diseases and their carers face stigma and discrimination, which makes their daily lives and health care difficult. I want to do all that I can to promote the rights of people with memory disabling diseases, help and facilitate good quality care for them, and try to support best practices in medical care for everybody.”
Jesús Rodrigo (Spain)

Jesús has a Degree in Sciences of Education and has spent his entire professional career in non-profit organisations, in positions of increasing responsibility.

He is currently the Executive Director of the Spanish Confederation of Associations of Families of People with Alzheimer’s and other Dementias (CEAFA), a position he has held since 2005. Working directly with the Board, he has contributed to developing the various strategic plans of the organisation and in positioning the entity as a reference to the Central Government of Spain with regards the definition of a national dementia strategy.

Jesús joined the Board of Alzheimer Europe in 2014:

“In the work with my colleagues on the Alzheimer Europe Board, I will respond to ongoing inquiries that will arise about fundraising, strategic partner relationships and policy discussions concerning legal and economic issues concerning persons with cognitive decline.”

Karin Westerlund (Sweden) – New member

Karin holds an Executive MBA from Stockholm School of Economics and a Bachelor Degree in financial economics from Stockholm University.

Karin’s work for Alzheimer Sweden started in 2015 with a 3-year inquiry about persons with Alzheimer’s disease and Down Syndrome. Today, she works as a Consultant and Investigator for the organisation, focussing on the dialogue with the concerned Swedish Public authorities:

“In the work with my colleagues on the Alzheimer Europe Board, I will respond to ongoing inquiries that will arise about fundraising, strategic partner relationships and policy discussions concerning legal and economic issues concerning persons with cognitive decline.”

Farewell to three former Board members

Alzheimer Europe wishes to thank outgoing Board members Marie-Odile Desana (France), Sabine Henry (Belgium) and Štefanija Lukič Zlobec (Slovenia) for their service.

Two new member organisations

Also during the 2018 AGM, Alzheimer Europe was pleased to welcome two new provisional member organisations:

Alzheimer Disease Association of Macedonia and NGO Living with Dementia, Estonia were formally voted in, bringing the number of Alzheimer Europe members to 42, hailing from 37 countries.
Alzheimer Europe hosts the 4th edition of its annual Alzheimer’s Association Academy

On 4 and 5 December 2018, Alzheimer Europe hosted its 4th Alzheimer’s Association Academy, in Brussels. Topic areas were chosen based on a survey of participants at the 2017 Academy and member organisations.

Alzheimer Europe’s 4th Alzheimer’s Association Academy involved 9 experts from various European and national institutions/organisations. Participants included 31 representatives from Alzheimer Europe’s member organisations; 4 company representatives; 4 members of the European Working Group of People with Dementia (EWGPWD) and 7 Alzheimer Europe staff members.

Involving carers

The first day began with a session on “Involving carers of people with dementia in Alzheimer’s associations” and was moderated by James Pearson, from Alzheimer Scotland. This session included presentations by Štefanija Lukič Zlobec (Spominčica, Slovenia), who spoke about the experience of Spominčica in involving and supporting carers of people with dementia; Bernard O’Hagan (National Dementia Carers Action Network – NDCAN, Scotland, UK), who told delegates about the experiences of carers of people with dementia advocating for policy change at national level in Scotland; and Mario Possenti (Federazione Alzheimer Italia, Italy), who shared the experience of Federazione Alzheimer Italia in surveying the views of carers of people with dementia. During their presentations the speakers addressed key questions such as: How can Alzheimer’s associations effectively involve carers of people with dementia in their governance and activities? How should Alzheimer Europe effectively involve carers of people with dementia in its governance and activities? and how are the interests of people with dementia and of carers represented by Alzheimer’s associations?
Involving people with dementia

The second session of the day was on “Giving a voice to and involving people with dementia in Alzheimer’s associations” and was moderated by Iva Holmerová, Chairperson, Alzheimer Europe. This session included presentations by Dianne Gove (Alzheimer Europe), who discussed the findings of Alzheimer Europe’s mapping exercise on the development and growth of working groups of people with dementia in the European region and Jesús Rodrigo (CEAFA, Spain), who spoke about PEPA, the Spanish Group of People with dementia, as an example of a recently-created working group. The speakers looked at how national organisations can better involve people with dementia in their governance and activities, and at some of the barriers identified.

Introduction of Alzheimer’s treatments/innovations – Some challenges

Day two of the Academy began with a session on “Challenges for the introduction of Alzheimer’s innovation”, which was moderated by Jean Georges, Executive Director, Alzheimer Europe. This session included presentations by Tim Shakespeare (Alzheimer’s Society, United Kingdom), who shared Alzheimer’s Society’s experience on preparing for the introduction of new Alzheimer’s medicines; Andy Bolan (Biogen), who discussed “Health System Preparedness of Six EU Countries for future Alzheimer’s innovation”; and Krista Tromp (Erasmus Medical Centre, Netherlands), who spoke about how the introduction of preventative treatments impacts the ethical issues raised by genetic and biomarker risk disclosure.

All three presentations helped to give the delegates at the Academy a clearer picture of how the introduction of disease-modifying treatments impacts on the role of Alzheimer’s associations, how healthcare professionals need to respond to the introduction of new treatments, whether healthcare systems have the necessary infrastructure and procedures in place for the introduction of new medicines, and how society might respond to the introduction of these medicines as well as ethical issues that would need to be addressed.

Participation in dementia research

The second morning session was on “Promoting the participation of people in dementia research”, with moderator Charles Scerri of the Malta Dementia Society. This session included presentations by Ana Belén Callado Gil (Fundació Pasqual Maragall, Spain), who gave examples of the effective use of communication to increase research participation; Marissa Zwan (VUMC, Netherlands), who presented “Hersenonderzoek” – the Dutch registry for brain research and nationwide online platform for recruitment and pre-screening of participants for neuroscience studies and Piers Kotting (Join Dementia Research, UK), on increasing the participation of people in dementia research, using Join dementia research as an example. This session introduced some of the initiatives at national level to promote the involvement of people with dementia, carers and people at risk of developing dementia in dementia research, the role Alzheimer’s associations have in promoting opportunities for research participation, and whether or not it could be feasible to encourage common systems or databases for people interested in participating in dementia research.

PRODEMOS project consultation

The final session of the Academy was a consultation with the “Prevention of dementia using mobile phone applications project” (PRODEMOS) moderated by Krista Tromp. The PRODEMOS project aims to develop an evidence-based dementia prevention strategy using mobile health and making it accessible to those at increased risk of dementia who are usually not reached by preventive medicine. It is targeting socio-economically deprived populations in the EU and a population at risk of dementia in China. The final aim is to implement a flexible, fully-adaptable mHealth platform in a culturally appropriate form in a range of healthcare settings across the globe. Project researchers Marieke Hoevenaar-Blom, Edme Eggink, both at Amsterdam Medical Centre, and Shanu Sadhwani (University of Sussex) asked delegates to reflect on a number of questions related to the app and some of the possible difficulties that they might encounter in creating and implementing it, as well as coming up with solutions and other ideas.

Looking forward to the fifth Academy

The two-day Academy was a very interactive event, with plenty of interesting and thought-provoking discussions. Given the success of its Alzheimer’s Association Academies to date, AE will host a fifth edition in December 2019.
Comparing dementia strategies across Europe

Following the publication of Alzheimer Europe's 2018 yearbook comparing dementia strategies in countries in Europe, Owen Miller, Policy Officer, gives an overview of the report and some of the key points within it.

At the 24th Alzheimer Europe Conference in Glasgow in 2014, The Glasgow Declaration was launched, calling for the creation of a European Dementia Strategy and for the development of national strategies in every European country. The signatories also called upon world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia.

Since then, a considerable number of national governments have published national dementia strategies. Almost five years on from the Glasgow Declaration, our 2018 yearbook has been published, comparing 21 dementia strategies (or national plans) and two neurodegenerative strategies across European countries, with a specific view to providing a comparative overview of the priorities and areas of focus. Doing so has allowed us to establish not only what areas of dementia policy and practice are being prioritised by national governments, but also the diversity of approaches to these issues. The main body of the report is broken down into five main headings, which are then further subdivided into specific subject areas. The five main headings are:

- Development and implementation of strategies
- Human rights and legal matters
- Diagnosis, post diagnostic support, care and treatment
- Informal carers
- Research.

These headings reflect the most frequently recurring themes across all of the strategies reviewed, regardless of differences in terms of population size, economic status or healthcare systems.

Specifically, considering the commitments and policies contained within the strategies, it is apparent that the greatest number relate to the provision of health and social care services for people with dementia. This includes a focus on care coordination, diagnosis, treatment and the training of health and social care practitioners. Aside from these service-focused commitments, awareness raising amongst the public and improved infrastructure and resources for research were also areas of significant focus for many of the strategies.

One point we are keen to emphasise about the report is that its analysis of the policies and commitments within the strategies, it is apparent that the greatest number relate to the provision of health and social care services for people with dementia. This includes a focus on care coordination, diagnosis, treatment and the training of health and social care practitioners. Aside from these service-focused commitments, awareness raising amongst the public and improved infrastructure and resources for research were also areas of significant focus for many of the strategies.

On behalf of Alzheimer Europe, I would like to thank members who took the time to review drafts of the yearbook and suggested changes and amendments with this work – this was invaluable in ensuring the report was as accurate as possible. I would also like to extend our thanks to members of the European Working Group of People with Dementia (EWGPWD) who took time to share their personal views and experiences in relation to specific themes identified within the strategies. Their contributions within the report illustrate that without good implementation of the policies and commitments within the strategies, it will be impossible to meaningfully improve the lives and experiences of people with dementia, their families and carers.

The report has now been published in English and copies can be ordered from: www.alzheimer-europe.org/Publications
Table 1: National dementia strategies at a glance

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* Implementation refers to whether the strategy outline implementation or governance measures – it does not refer to the status of implementation of the strategy.

TRANSFORMING THE LANGUAGE OF LIFE INTO VITAL MEDICINES

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Amgen is proud to support Alzheimer Europe

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Promoting intercultural dementia care and support in Europe

Following the publication of Alzheimer Europe's 2018 report examining the experiences of people from minority ethnic backgrounds with dementia, Dianne Gove, Director for Projects with Alzheimer Europe gives an overview of the background to the report and some of the key themes.

An increasing number of people from minority ethnic groups are reaching an age at which the risk of developing dementia is higher and this trend is predicted to continue in the next few decades. At the same time, people from minority ethnic groups tend to use fewer services than their counterparts from the majority ethnic groups in different countries. This applies to most forms of support and care but is particularly noticeable in the context of residential care, even though many people from minority ethnic groups are employed in residential care homes.

It is clear from the literature that there are several factors that may contribute towards the low uptake of services and support such as distrust, lack of awareness, how dementia is understood, low levels of literacy, lack of fluency in the national language, fear that traditions and practices will not be supported and financial issues. Moreover, it is sometimes assumed that people from minority ethnic groups don’t need support, based on the assumption that “they look after their own”. This is a stereotype which needs to be challenged and different approaches to care and support explored, together with people from different ethnic groups, in order to develop support that is culturally appropriate and acceptable. All too often, care and support are provided within a framework which reflects the cultural traditions, norms and assumptions of majority ethnic groups.

In 2018, Alzheimer Europe set up an expert working group to write a comprehensive report aimed at improving the situation of people with dementia, their carers and professional carers from minority ethnic backgrounds through the identification and promotion of intercultural care and support. Members of the working group, with different expertise and experience in the field and from a range of ethnic groups, worked tirelessly throughout 2018 to produce the report. They also provided a brief overview of some of the key sections of the report at a special symposium during the 28th Alzheimer Europe Conference in Barcelona. Topics presented included: the prevalence, assessment and diagnosis of dementia in minority ethnic groups; interpreter-mediated dementia assessments of people from minority ethnic groups; working with and involving local minority ethnic groups in the development of intercultural care and support; examples of activities and support for people from specific minority ethnic groups provided by Alzheimer associations and issues surrounding live-in/migrant carers for people with dementia.

On behalf of Alzheimer Europe, I would like to thank the members of the working group, which I had the pleasure to chair. The members of the group donated their time, expertise and personal experience in the field and in so doing, made it possible for Alzheimer Europe to accomplish this important work. The members of the group were (in alphabetical order) Jean Georges (Luxembourg), Michal Herz (Israel), Siiri Jaakson (Finland), Ripaljeet Kaur (UK), Debi Lahav (Israel), T. Rune Nielsen (Denmark), Sahdia Parveen (UK), Charlotta Plejert (Sweden), Mohammed Akhlak Rauf (UK), Daphna Golan Shemesh (Israel) and Carolien Smits (Netherlands).
**Governmental Expert Group on Dementia meets for first time**

Following the decision of the European Commission to disband its own Governmental Expert Group on Dementia in 2018, Alzheimer Europe worked with the Dutch, Italian and Scottish Governments to re-establish a similar group bringing together nominated national experts to share information and expertise.

A new Governmental Expert Group on Dementia met for the first time since the European Commission disbanded a similar group in summer 2018. The meetings took place on 3–4 December 2018 in Brussels, bringing together government-nominated representatives from across Europe to discuss progress and developments in relation to dementia policy, practice and research. Facilitated by Alzheimer Europe, the Dutch Ministry of Health, Welfare and Sport, the Italian Ministry of Health and the Scottish Government, the group was brought together after initial discussions between these members resulted in agreement that losing the European Commission Expert Group would be detrimental, as no other platform existed in which governments exchange knowledge and information on dementia.

In total, 17 governments attended the group, with apologies received from a further 6 who expressed an interest in participating in future meetings. 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 Organization (WHO).

### Countries update on their dementia strategies

To improve the understanding between members of the group, each country presented on the status of dementia policy and practice in their country. In a number of cases, countries referred to their national dementia strategy and the specific provisions laid out therein. It was notable that whilst there were significant challenges and difficulties which were specific to countries, difficulties such as the lack of good quality statistics and data, as well as the rising demand for services and supports due to demographic changes, were common across nearly all countries.

Additionally, members heard from observer organisations who presented on relevant developments from their organisations, the Commission’s update on EU funding for dementia-specific research (primarily through the Horizon 2020 programme and through the future Horizon Europe programme), the OECD’s report into dementia policies across OECD nations and the WHO’s Global Action Plan on Dementia 2017–2025.

### Second Joint Action on Dementia

Members of the group also heard from work package leaders from the second Joint Action on Dementia who presented on the progress of work underway as part of the programme. The presentations were focused on their respective work packages: diagnosis and post-diagnostic support; crisis and care coordination; residential care; and dementia friendly communities. Members agreed that this would be a useful forum in which to distribute the results and findings of the Joint Action to as broad an audience as possible and to have a meaningful impact.

### Future meetings of the group

The group agreed that it would be worthwhile to meet twice per year, with sessions dedicated to exploring specific themes and areas of work, such as care coordination or diagnosis. Alzheimer Europe will continue to provide a secretariat role for the organisation and meetings of the group.
Dementia as a European priority – A timeline of key developments since 2014

Since 2014, a great deal of progress has been made towards making dementia a European priority. Here we set out some of the key milestones, both positive and negative, that have taken place in recent years, starting from the signing of the Glasgow Declaration in 2014.

Glasgow Declaration (2014) – The Glasgow Declaration called for the creation of a European Dementia Strategy and national strategies in every country in Europe. The declaration also called for world leaders to recognise dementia as a public health priority and to develop a global action plan on dementia. Over 11,600 individuals signed the declaration, with more than 200 organisations and in excess of 150 policy makers showing their support by signing the pledge.

Horizon 2020 (2014–2020) – This programme is the biggest EU Research and Innovation programme, with approximately EUR 80 Billion of funding available over 7 years, aiming to deliver more breakthroughs and discoveries in research.

Innovative Medicines Initiatives 1 & 2 (2008–2013 & 2014–2020) – As part of Horizon 2020, the IMI2 is a continuation of the original IMI scheme, representing the largest public-private medicines initiative in the world. It was officially launched in July 2014 and has funded a number of key dementia research projects, including EPAD, AMYPAD, ROADMAP and PARADIGM, all of which involve Alzheimer Europe.

European Parliament Written Declarations (2015 and 2016) – Two Written Declarations were made with the support of MEPs in the European Alzheimer’s Alliance in 2015 and 2016. The 2015 declaration encouraged both the European Council and the European Commission to prioritise greater collaboration in research, care and prevention. The 2016 declaration called for dementia to be recognised as a public health priority, as well as identifying the need for a strategy to meet challenges presented by dementia.

EPSCO Council adopts Luxembourg EU Presidency Conclusions (2015) – The Employment, Social Policy, Health and Consumer Affairs (EPSCO) Council of the Luxembourg EU Presidency, adopted conclusions on a number of health-related items, including conclusions on “Supporting people living with dementia”. One of these included calling on all Member States to address dementia as a priority, to develop national strategies or actions plans and to strengthen the collaboration between European countries.

Second European Joint Action on Dementia (2016–2019) – Following ALCOVE (Alzheimer Cooperative Valuation in Europe – the first “Joint Action on Dementia”), the European Commission supported the launch of a second Joint Action through its Health Programme. The Joint Action aims to promote collaborative actions among Member States to improve the lives of people living with dementia and their carers, and focuses on four key areas: Diagnosis and post-diagnostic support; Crisis and care coordination; Residential care; and Dementia-friendly communities.

European Social Pillar (2017) – The European Social Pillar, proclaimed by EU Members in 2017, sets out 20 principles in three areas: Equal Opportunities and Access to the Labour Market; Fair Working Conditions and Social Protection and Inclusion. As part of this, the Commission is currently drafting a directive in relation to Principle Nine, “Work-Life Balance”, which would give carers the right to five days of paid leave each year.

Alzheimer Europe Carers’ Survey (2018) – In June 2018, at a lunch debate in the European Parliament, Alzheimer Europe presented the final findings from the European Carers’ Survey, which explored the experience of carers in the diagnostics and post-diagnostic processes in five countries across Europe. The results showed that the process of diagnosis is still taking too long and carers often do not receive adequate support after the diagnosis has been made.

Governmental Expert Group on Dementia (2018) – Following the decision of the European Commission to disband condition specific Governmental Expert Groups in the summer of 2018, Alzheimer Europe worked with representatives from the Dutch, Italian and Scottish Governments to reconvene a Governmental Expert Group. You can read about the inaugural meeting on the previous page.
European Alzheimer’s Alliance members share their thoughts on making dementia a European priority

As the current term of the European Commission comes to an end and with the European Parliament elections in May 2019, we asked members of the European Alzheimer’s Alliance to reflect on progress towards making dementia a European priority.

As the timeline on page 16 shows, much progress has been made at a European level over the past 5 years to ensure that dementia remains a European priority. However, we must continue to work to make sure that this progress is not lost.

The current political and policy context means there will be a lot of significant developments in a short space of time including changes to the Commissioners who lead each directorate, the ongoing negotiations on the Multiannual Financial Framework (MFF) which will determine the future budgets of the EU (including the place of health), the future Horizon Europe (2021–2027) research programme and the European Parliament elections in May 2019. This provides both opportunities and challenges for dementia as a European priority.

As such, we asked members of the European Alzheimer’s Alliance (EAA) to reflect and share their thoughts on:

- What they considered as the key achievements at an EU level in the recognition of dementia as a European priority.
- What they believed the European Union could do to further support people with dementia and their carers in future health, research and social programmes.
- What they saw as the greatest achievement/contribution of the EAA over the past five years.

Sirpa Pietikäinen (EPP, Finland) – Vice Chair of EAA

Key achievements include the European Commission’s initiative on Alzheimer’s disease and other dementias and the pushing forward of the creation of national Alzheimer’s programmes at the Member States level. It has also been a key to have an inclusive and broad roadmap with regards to how memory disabling diseases could be better treated and the daily lives of people improved.

Further support can be shown by:

- Making dementia one of the health priorities in the Horizon Europe research programme
- Creating an informal carers programme at the European level to address the following priorities:
  - Recognition: personal and societal recognition of carers
  - Acknowledgement: recognition as a carer leading to certain status for carers, which would determine rights and obligations
  - Support: Based on certain criteria, right to defined social support
  - Work Life Balance: guaranteed right to combine carer’s role with formal employment
- Services: Support services including time-off for the carer
- Rehabilitation: Including health promotion and protection for the carer, on par with occupational health services.
- Pairing-up work on Alzheimer’s programmes with the development of user friendly e-health technologies that are accessible, developed with the full participation, from the beginning, of intended users.

The greatest contribution of the EAA has been building up the work of the European Dementia Ethics Network, as well as the close follow-up and monitoring of the development and implementation of national strategies to address memory disabling diseases in various Member States.

Martina Anderson (GUE/NGL, UK) – Member of EAA

Dementia has wide-ranging consequences for those living with the condition, for their families and carers and society as a whole. Much remains to be done, maintaining a consistent focus on support mechanisms for people diagnosed with dementia and their carers, full access to home-care where needed and addressing the stigma attached to the condition. I have met with representatives from national Non-Government Organisations (NGOS), alongside signing the 2016 parliamentary declaration and the pledge ran by Alzheimer Europe.

European funding for local organisations is vital to their development and capability to support citizens living with dementia, their families, safe community schemes and carers. Funding streams for national organisations should be developed as oftentimes charities and NGOs are providing the dominant support system. Organisations caring for citizens with dementia in the north of Ireland should not suffer any diminution of such support in the context of Brexit. Europe should further focus funding and support in a research capacity, recognising that the Commission funds research projects on Alzheimer’s and...
neurodegenerative diseases through the 7th Research Framework Programme.

It is a credit that the EAA has made this issue a priority. It assists in sharing developments in relation to research, support systems and developments in the treatment of Alzheimer’s. This body in association with local organisations such as The Alzheimer Society of Ireland and Dementia NI, provide consistent pressure for much-needed change. We need to develop understanding of the practical impact of dementia, alongside the psychological and emotional impact – and support carers to look after themselves when supporting someone with dementia.

**Matt Carthy (GUE/NGL, Ireland) – Member of EAA**

The inclusion of dementia in the European Council’s conclusions in 2015 was an important step in raising the profile of this sometimes hidden disease with policy makers. Of the 48,000 people living with dementia in Ireland, it is estimated that 63% of them reside in their own homes. The number of people developing dementia is rising every year, and is expected to more than double by 2040. While healthcare is not an EU competence, it is important for the issue to be raised through multilateral fora since the breadth of actions to address these challenges as our populations continue to age must be coordinated. At national level though, we need to urgently start addressing funding gaps in healthcare to ensure that people affected and those caring for them are protected.

The European Parliament’s 2011 resolution calling for specific national plans and strategies to facilitate funding has, for the most part, been realised. A National Dementia Strategy was published in my home country (Ireland) in 2015, however full implementation of the strategy remains an issue. While the vast majority of actions such as the provision of funds for care, housing adaptation, and training for early diagnosis will take place through national health strategies, the EU should look to play a role in facilitating complementary research in health care and research institutions across Europe. No new medicines have been approved for dementia in over a decade, therefore cooperation to encourage studies daunted by huge investment costs is vital.

**Deirdre Clune (EPP, Ireland) – Member of EAA**

One of the major achievements at EU level in recognising that dementia is a priority is ensuring that all countries develop a dementia strategy. We are not there yet but I am confident that all EU countries will develop such a strategy and thus implement policies recognised at EU level that will improve the lives of those with dementia and their carers.

To further support those with dementia we should encourage collaboration and sharing of best practice in helping those with dementia to better manage day to day living. Research that focuses on social programmes should receive a balanced share of funding and support.

The EAA has raised awareness and ensured that public representatives care, understand and are willing to support policies that improve the lives of those with dementia, recognising the important role played by carers.

**Marian Harkin (ALDE, Ireland) – Member of EAA**

In terms of the EU level achievements, the joint Programme – Neurodegenerative Disease Research is the largest global research initiative, focusing on improving scientific understanding, medical tools to identify and treat Alzheimer’s, and social care structures.

The EU can further work to ensure greater collaboration between Member States in research and sharing of best practice. Additionally, it can facilitate the involvement of patient’s organisations in policymaking. Furthermore, it can agree on the Work-Life Balance proposal to ensure carers’ leave and more flexible working conditions.

The EAA has managed to put Alzheimer’s firmly on the EU Agenda and make it a European priority.

**Karin Kadenbach (S&D, Austria) – Member of EAA**

Dementia has been a European priority for nearly ten years now. The first step by the Parliament was set by adopting the written declaration 80/2008. Since then dementia has been on the European agenda many times, such as the council communication in 2015, which welcomed the second Joint Action on Dementia. One project which I would like to highlight is “Horizon 2020”. The research done during this project is especially important for tackling dementia in the future. Specifically for Alzheimer’s, the EU spent EUR 544 Million in 370 projects over the past 10 years.

In my opinion, the most important action to support people with dementia and their carers is information. Many people do not know what a broad field of opportunities exists. The programmes have to be available and easily accessible for everybody. Otherwise, many people living with dementia will be excluded in the process of health, research and social programmes. I am happy that Member States and other stakeholders can now consult the “best practice portal” (launched in April 2018), practices selected under the second Joint Action on dementia.

The work of the EAA in line with Alzheimer Europe’s strategic plan has been the main achievement in recent years. The five objectives that are tackled within are the most important in the fight against dementia, especially providing a voice to people with dementia and supporting research in this field, as these have a major influence on the fight against dementia and Alzheimer’s.

**Merja Kyllönen (GUE/NGL, Finland) – Member of EAA**

Getting dementia recognised in the research agenda and highlighting dementia as a major public health and social care issue has been a key achievement, as it has sharing the knowledge and information around Europe. Additionally, getting the Commission, Parliament and
Council to take dementia and its effects seriously, has been crucial.

The EU must finance the programmes to find new treatments, medicines and innovative healthcare equipment. It must also finance programmes that support the wellbeing of carers as well as patients.

The EAA has made an excellent co-operation with parliamentarians to share knowledge and existing information about dementia and its effects to citizens, as well as the latest advances in scientific research and what needs to be done in this important area.

Paul Rübig (EPP, Austria) – Member of EAA

The European Union is dedicated to fight diseases and to improve health and life of its citizens. The main key for that is Europe’s support for research and innovation in the health and medical sector. In STOA, the scientific committee within the European Parliament, we focused on that topic (for example with a Brain Awareness campaign) as improvement in technology for healthcare and medicine is crucial when it comes to a society that gets older. For this we need better connectivity between researchers, universities, laboratories and health centres like hospitals combined with more investments in research and development of technology.

Hilde Vautmans (ALDE, Belgium) – Member of EAA

Through the Act on Dementia Joint Action, and other initiatives the EU has put dementia higher on the agenda and encouraged Member States to develop national identification and treatment strategies. Similarly, it set up information-exchange and expert cooperation mechanisms in which government officials can exchange best practices and work towards a better treatment of this disease. The key achievement really is its response to a public cry for increased action and effective measures. Since 2006 dementia has been moving up the EU agenda, which means it receives more attention and funding.

Despite the gathered research and growing availability of data, several frontline actors such as the European Federation of Nurses Associations are not sufficiently included in the policy-making process, which is problematic since those actors are most exposed to the real challenges of dementia. The EU could also give more priority to dementia by establishing, for example, a dementia coordinator at EU level. Similarly, it could do more to spur collaboration between health and social ministries and set up a comprehensive research agenda that gathers all stakeholders for an informed debate on the real implications of the disease.

The real merit of the EAA is that it puts dementia in the spotlight, raising awareness on a national and European level about the urgent need for a comprehensive approach. By gathering potential stakeholders it managed to trigger a greater exchange of information and best practices. Similarly, it was effective in lobbying dementia higher up the EU agenda, which led to increased funding and research. Therefore, the greatest achievement of the EAA is to serve as the glue that connects all players in the field.

Julie Ward (S&D, UK) – Member of EAA

Regarding key achievements we must applaud the 2015 Luxembourg Presidency for being explicit about the way in which dementia impacts many areas of life, not just the affected person but the wider family, community and society as a whole. The Presidency’s statement that the human rights of people with dementia must be respected was an important reminder that we are dealing with people who still have lives to lead, albeit in challenging circumstances. I was pleased to see the Presidency’s call for a gender-sensitive approach to research. This mirrors my own work on disability, women and mental health and the promotion of intersectionality as a means of recognising multiple discrimination.

The adoption of the EU Social Pillar in Gothenburg in 2017 was a crucial step towards putting people back at the heart of the European project. Empowering citizens to participate in decision-making about their health and well-being must extend to people with dementia and their carers. This means addressing issues of education and poverty. The European Parliament has been very proactive in its approach to the Commission’s proposal for a Work-Life Balance Directive which would give carers paid leave. We now require action from the Council to make this a reality and transform the lives of millions of caregivers.

The greatest achievement of the European Alzheimer’s Alliance during the current legislature has been the increased level of awareness amongst politicians about the importance of evidence-based policy-making and the role of experts, including those with lived experience of dementia. This is demonstrated by the strong wording of the Written Question to the Commission regarding the dismantling of the Expert Working Group. Despite the Commission’s disappointing answer the Alliance is in a strong position to bring the fight to the next legislature, building on the many excellent joint initiatives and increased networking between Member State organisations. The issues provoked by dementia and our ageing society will not be going away soon!

The European Alzheimer’s Alliance has been active in the European Parliament since 2007. 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.

The mission of the group 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. It also seeks to promote actions to give dementia priority at European and national level.

The group currently has 126 members from 27 EU Members States.
Alzheimer Europe launches European Dementia Pledge for the European Parliament Elections – Get involved!

Alzheimer Europe has launched its Election Campaign for the European Parliament Elections (23 May – 26 May), asking candidates to sign our pledge committing them to make dementia a European priority.

Alzheimer Europe is pleased to launch its Election Campaign for the European Parliament Elections, which will take place between 23 May and 26 May 2019.

As for previous European elections, Alzheimer Europe, with the support of our members, will ask every person standing as a candidate for the European Parliament to show their commitment to supporting people with dementia, their families and carers by signing up to the pledge.

Alzheimer Europe has put together a social media pack in order to target candidates, which has been shared with our members, as have translated versions of the pledge, in each of the 27 languages of the EU. Alzheimer Europe will campaign primarily through social media, but will also raise awareness and encourage others to contact their national candidates through our newsletter and other channels.

We will also, on an ongoing basis, update the Alzheimer Europe website to show which candidates have signed up, listed by country, and including information on the candidate’s national party, European Party and a link to their website/social media platform.

These elections are crucial as they are the first step in our work to ensure that elected decision-makers at an EU level understand how they can make a difference to the lives of people with dementia, their families and carers.

By encouraging candidates to sign up to the pledge, it gives us a strong basis on which to follow up with successful candidates after the election has taken place.

For details on the election pledge, campaign resources and other relevant information, please visit the Alzheimer Europe website.

Changes to number of elected MEPs

It is useful to note that as a result of the UK’s exit from the European Union, there has been a reallocation of some of the seats resulting in a change in the allocation of MEPs for some countries. Whilst there were a total of 751 MEPs elected in the 2014 election, at the 2019 election, there will be only 705 MEPs elected.

The table below shows how many MEPs will be elected in each country in 2019 – the number in brackets shows how many MEPs the country currently has.

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European Institutions reach agreement over European Accessibility Act

The European Parliament and the Council have, after a number of years of negotiation, reached political agreement over the scope of a new directive aimed at improving the lives of people with disabilities. The European Accessibility Act aims to improve accessibility for a range of goods and services, whilst reducing divergent legislation across the EU.

More than 80 million people in the EU are affected by a disability to some degree, with around 9 million estimated to have some form of dementia. The accessibility of goods, services and places is a precondition for equal participation in day-to-day life. As such, the European Accessibility Act was first proposed by the European Commission in December 2015, in order to bring benefits both for persons with disabilities and for businesses producing relevant products and services.

The Accessibility Act

After many years of negotiation, on 8 November 2018, the European Parliament and the Council came to a provisional agreement on revisions to the Commission’s initial proposal. The Act aims to improve the functioning of the internal market for accessible products and services, by removing barriers created by divergent legislation through the establishment of European-wide functional requirements. This will be achieved through accessibility principles, rather than prescriptive detailed technical solutions, applicable to:

- Computers and operating systems
- ATMs, ticketing and check-in machines
- Smartphones
- TV equipment related to digital television services
- Telephony services and related equipment
- Audiovisual media services such as television broadcast and related consumer equipment
- Services related to air, bus, rail and waterborne passenger transport
- Banking services
- E-books
- E-commerce.

The European Accessibility Act will facilitate the work of companies, and aims to bring benefits for persons with disabilities and elderly people in the EU. Businesses will benefit from the elimination of barriers caused by a fragmented market, thanks to the creation of a single set of requirements, which will simplify cross-border trade.

Exemptions

There is a feeling, amongst some, that the Act did not go far enough and failed to live up to its name. For example, the European Disability Forum (EDF) highlighted that the Act omitted key areas, which are vital in allowing people with disabilities to go about everyday life, including transport or accessible buildings and infrastructure. Yannis Vardakastanis, MEP President of the EDF stated that “EU Member States need to go above and beyond the scope of the Act if they want it to make a difference. They need to ensure that persons with disabilities have the same access to places, products and services as everybody else.”

Accessibility requirements, for example with regard to ramps, doors, public toilets and staircases, currently vary across EU countries. In order to make the built environment “continuously and progressively more accessible” to persons with disabilities, Member States are encouraged to align their diverging requirements as much as possible. The co-legislators introduced a review clause requiring the Commission to assess the situation five years after the application of the Directive.

Micro-enterprises (organisations with fewer than 10 employees) that provide services are exempted from the Directive and those providing products will be exempted from some obligations to avoid imposing a “disproportionate burden” on them. Member States will have to provide guidelines to micro-enterprises in order to facilitate the implementation of this legislation.

The Act provides an important step forward towards the inclusion of persons with disabilities. However, it would undoubtedly benefit from accessibility criteria, incorporating the built environment and transport.

The provisional agreement will be submitted to the Council’s Permanent Representatives Committee for approval. Once the Member States’ Permanent Representatives confirm the agreement, the European Parliament will vote in the plenary session and the Council will conclude by the final adoption.

EU Member States need to go above and beyond the scope of the Act if they want it to make a difference. They need to ensure that persons with disabilities have the same access to places, products and services as everybody else.”

Yannis Vardakastanis
Commissioner Marianne Thyssen speaks to Alzheimer Europe about the progress of key social reforms at an EU-level

Commissioner for Employment, Skills, Social Affairs and Labour Mobility, Marianne Thyssen, has spoken to Alzheimer Europe to provide an update on areas of work such as the European Social Pillar and Work-Life Balance initiative, and how these aim to improve the experience for people with dementia, their families and carers.

Over one year has passed since the adoption of the European Pillar of Social Rights, what progress has been made to realising its principles?

The proclamation last year by the three political European institutions was not the end but the beginning of a process, a commitment to work together to reach our goals. This is what we have been doing – we are implementing the Pillar together at all levels: local, national and European, together as public authorities, social partners and Non-Governmental Organisations (NGOs). As Commission, we launched a number of proposals and we are working very hard with the Council and the Parliament, to finalise them. One example is to ensure that everybody can have access to social protection that Member States provide for adequate and effective coverage. Another example to enable men and women to reconcile work with caring obligations. Our Work-Life Balance proposal is of particular importance to people living with dementia and their carers. It includes provisions for carer’s leave and the right to request flexible working arrangements for people caring for a dependent relative.

A milestone was reached in November, when the European Parliament and the Council came to a provisional agreement on our proposal for a European Accessibility Act. This new legislation will make many everyday products and services, such as phones, banking services and the 112 emergency number, accessible to persons with disabilities and older people. To make the Pillar a reality on the ground, for tangible results and a meaningful impact in the everyday lives of Europeans, we have to continue our action at all levels. European countries must continue their efforts, in close cooperation with social partners and civil society. The European Commission is steering this process through the European Semester, the annual cycle of social and economic policy coordination. Furthermore, the Commission monitors performance in each Member State and steers the process of upwards convergence through the social scoreboard.

As the Work-Life Balance initiative moves into the negotiation stage between the Commission, Parliament and Council, what is your hope for the final version of the initiative and what is the expected timeline for implementation?

The key objective of the Work-Life Balance initiative is to address women’s under-representation in the labour market by promoting the equal sharing of caring responsibilities between women and men. Without this initiative, we are offering more possibilities for parents and carers to reconcile their professional and caring responsibilities. My ultimate goal is that women and men can care for loved ones with dementia without having to give up or slow down their careers. Our proposal for a Directive is currently under negotiation by the European Parliament and the Council, who have the common ambition to find agreement in the next weeks. The precise timeline for implementation will depend on the final agreement between the co-legislators.

What do you believe remains the single greatest challenge in ensuring that people with dementia and their carers, remain active citizens within their communities?

As Europe’s population is ageing, the number of people with dementia is on the rise. Finding a suitable cure might stop this increase. In the meantime, people with dementia need quality care to help them manage their condition, avoid unnecessary hospitalisations and stay as independent as possible. Maintaining social ties is particularly important, as loneliness and isolation can accelerate the progression of the disease.

Receiving a diagnosis of Alzheimer’s disease or being faced with symptoms of dementia can be a shock to patients and their families, who often have to manage on their own. Targeted support for people living with dementia and carers is therefore vital. It should be provided in a coordinated way to avoid that people living with dementia need to navigate the maze of different services in the already crumbling world they live in.

“My ultimate goal is that women and men can care for loved ones with dementia without having to give up or slow down their careers.”
Across Europe, there are a few dementia friendly initiatives, but more is needed. European funding for social innovation will hopefully pave the way for further bright ideas in providing care to people with dementia, while the new generation of Structural Funds should help turn these ideas into regular practice.

**In the context of the Multiannual Financial Framework (MFF), how do you see the future of the European Union’s activities in the social and health field?**

We want to strengthen the Union’s social dimension in the next long-term EU budget for 2021–2027. The Commission proposed a European Social Fund Plus with a budget of EUR 101 billion, geared towards investing in people. We want to ensure people are equipped with the right skills needed to deal with challenges and changes on the labour market, in line with the European Pillar of Social Rights. The European Social Fund Plus will merge existing funds in the social and health field. Combining different funds will help us tackle major challenges with a bigger impact. The new fund will for instance help European countries to test innovative solutions for the health systems of tomorrow. As budgets remain under pressure across Europe, the structural funds allow us to make wider investments, into peoples’ health, supporting longer-term outcomes that go beyond traditional health spending. For example, by educating young Europeans in healthy lifestyles we save lives and money in future. Investments to promote healthier work environments, or support for education and training programmes do the same.

**Profile**

Marianne Thyssen was appointed as the European Commissioner for Employment, Social Affairs, Skills and Labour Mobility in November 2014. She previously served as a Member of the European Parliament between 1991 and 2014.

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The Innovative Medicines Initiative celebrates ten years of breakthroughs

In October 2018, the Innovative Medicines Initiative (IMI) celebrated the 10th anniversary of its first call for proposals, showcasing the achievements of its projects through a communication campaign over several months.

What is IMI?

In 2007, the European Commission released a proposal for the creation of a public-private partnership between the European Community, represented by the European Commission and the European Federation of Pharmaceutical Industries and Associations (EFPIA).

The initiative aims to improve health by speeding up the development of, and patient access to, innovative medicines, particularly in areas where there is an unmet medical or social need. IMI projects aim to provide Europeans, including the increasing number of older people, with more efficient and effective medicines and treatments. IMI does this by facilitating the collaboration between the key players involved in health research, including academia, industry, small and medium-sized enterprises, patient organisations and medicines regulators.

IMI refers to two consecutive programmes: IMI1 (2008–2013) and IMI2 (2014–2020). During those 10 years, more than 100 projects have been carrying out ground-breaking work on a variety of topics, including severe asthma, Alzheimer’s disease, diabetes and cancer. These delivered numerous tools and resources as well as generating more than 4,000 publications to help researchers speed up the development of urgently needed treatments.

Following a detailed analysis of IMI’s first projects by independent experts into their socio-economic impacts, Carlos Moedas, European Commissioner for Research, Science and Innovation, said: “…IMI is delivering on its objectives. Public-private partnerships such as IMI are making the lives of Europeans better, create jobs and boost our competitiveness. They deliver results that single companies or countries could not achieve alone”.

IMI: Celebrating 10 Years of Medical Innovations

On 27 June 2018, over 400 people joined IMI, the European Commission and EFPIA for a celebration of IMI’s 10th anniversary at the European Commission in Brussels. The goal of the event was to highlight the successes of IMI projects, showcasing tangible results which have translated into concrete benefits for European citizens. During a plenary session, speakers from diverse backgrounds highlighted the way IMI has brought together people from universities, industry, small and medium-sized enterprises, patients, and regulators to tackle major research and healthcare challenges.

Project representatives described how IMI had contributed to specific results in their fields. Commissioner Moedas gave a talk and described the cultural shift this had brought about as one of the biggest achievements of IMI, and described IMI’s work as ‘radical collaboration’. In addition, the exhibition gave attendees the opportunity to meet IMI project participants and see first-hand IMI project results in areas such as cancer, antimicrobial resistance, Alzheimer’s disease, digital health and Ebola.

IMI Stakeholder Forum 2018

The subsequent IMI Stakeholder Forum 2018 took place on 24 October 2018 in Brussels under the banner “The value of cross-sectoral health research and innovation”. The event looked at IMI through the lens of cross-sector collaboration and discussed the added value of technology convergence to address complex health challenges, especially in those areas where there is a huge public health need.
Involvement of Alzheimer Europe

To mark this anniversary, IMI also prepared a series of videos with testimonials from its key partners and stakeholders. It launched several “Project Participant Testimonial” videos, for which Alzheimer Europe’s Executive Director, Jean Georges provided the perspective of a patient organisation.

Alzheimer Europe is uniquely placed to share the views and lived experience of people with dementia, to ensure ethical issues are taken into consideration and to help with the communication of project aims/achievements to the general public and its network of patient and carers’ organisations. Alzheimer Europe has been an active partner in many IMI dementia and Alzheimer’s disease focussed undertakings from the launch of the first dementia related project on.

Mr Georges commented on Alzheimer Europe’s involvement in IMI projects, highlighting that IMI’s patient-centric approach deepens collaboration between scientists and researchers and those who stand to benefit. People with dementia have been at the forefront of this trend. IMI lets Alzheimer Europe involve people with dementia in advisory roles within projects. This participation is vitally important; people with dementia are increasingly eager to be part of every decision that concerns their welfare and care. On page 26, we have included an overview of IMI projects in which Alzheimer Europe has been and is participating in as an active partner.

Dr Mathieu Boudes, PARADIGM Project Coordinator, European Patients’ Forum

“PARADIGM aims to participate in the co-creation of a framework to advance patient engagement in medicines development and therefore umbrella patient organisations such as Alzheimer Europe are key to bring in the perspectives of the members of those organisations in our work. It has a multiplying effect.”

Dr Laura Campo, MOPEAD Project Leader, Eli Lilly

“The MOPEAD Project aims to encourage a cultural shift towards a timely diagnosis of Alzheimer’s disease during the very early symptomatic stages of the disease. Ethical implications of an early diagnosis and external engagement are key components of the project. Alzheimer Europe, in a true spirit of collaboration, gave an invaluable contribution by producing the project’s ethics guidance and fostering an effective communication. This was a great benefit for the project and underscored the importance of value partnerships with patient organisations, with the ultimate and common goal to improve the environment for people living with Alzheimer’s disease.”

Dr Pierre Meulien, Executive Director, Innovative Medicines Initiative (IMI)

“Alzheimer’s disease represents a major challenge for public health, and we urgently need new strategies to prevent the onset of disease, slow its progression and, ultimately, cure it. However, the brain is extremely complex, and developing Alzheimer’s treatments is far from easy. We need to attack it at different levels, ranging from understanding the basic mechanisms of the disease, to stratifying patients, and defining strategies for early intervention. We also urgently need effective treatments for the psychiatric symptoms of Alzheimer’s disease.

A large-scale, multi-stakeholder, collaborative approach is essential if we want to make progress on these points, and patients and carers must be at the heart of these collaborations. As such, I am delighted that Alzheimer Europe is an active participant in so many of our projects. They do a fantastic job of bringing to the scientists the needs, opinions and knowledge of people with dementia. I know they also report back to their community as well as to the wider public on the results of our projects.”
Overview of IMI Projects

PharmaCog (2009–2011) Prediction of Cognitive Properties of New Drug Candidates for Neurodegenerative Diseases in Early Clinical Development. The project focussed on increasing the ability to predict new effective medicines from laboratory studies and clinical models.

www.alzheimer-europe.org/Research/PharmaCog
PharmaCog – grant agreement 115009

EMIF (2013–2017) The European Medical Information Framework project has connected data on 52 million individuals, deciphering links between genetic background, biological abnormalities, brain imaging changes, mental symptoms and disease progression.

www.emif.eu/
EMIF – grant agreement 115372


www.roadmap-alzheimer.org/
ROADMAP – grant agreement 116020


www.aetionomy.eu
AETIONOMY – grant agreement 115568

EPAD (2015–2020) European Prevention of Alzheimer’s Dementia. The goal of the initiative is the prevention of dementia in people with evidence of the disease (such as biomarker abnormalities) who still may have little or no complaints or clinical symptoms.

www.ep-ad.org/
EPAD – grant agreement 115736

AMYPAD (2016–2021) The “Amyloid imaging to prevent Alzheimer’s disease” project aims to improve the diagnostic workup of patients suspected to have Alzheimer’s disease and their management.

www.amypad.eu/
AMYPAD – grant agreement 115952

IMI acknowledgement
These projects, in which Alzheimer Europe is a project partner, receive funding from the Innovative Medicines Initiative and Innovative Medicines Initiative 2 Joint Undertakings. The Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.
German Government commits to developing national dementia strategy

The German Federal Government has announced its intention to develop a national dementia strategy for Germany, following the launch of the “Alliance for People with Dementia 2014–2018” report.

The German Federal Government has given its approval for the development of a German National Dementia Strategy. In September 2018, Federal Health Minister Jens Spahn of the Christian Democrats (CDU) and Federal Family Minister Franziska Giffey of the Socialists (SPD) announced the decision as part of the launch of the “Alliance for People with Dementia 2014–2018” report outlining some of the work on dementia, including around 450 projects, which have taken place across Germany over the past four years.

The “Alliance for People with Dementia” brings together federal, state and local umbrella organisations as well as more than 20 associations and institutions from the nursing and health sector, science and civil society, including the German Alzheimer’s association (Deutsche Alzheimer Gesellschaft – DALzG). Monika Kaus, Chairperson of the DALzG commented: “It is necessary to go on working together to support people with dementia and their families. For this work, resources are needed.”

1.7 million people currently live with dementia in Germany. Every year, the number of people with the condition is estimated to increase by about 40,000. Based on these projections, it is estimated that by the year 2050, the number of people diagnosed with Alzheimer’s disease or another form of other dementia will rise to over three million people.

Speaking at the launch of the new report Dr Giffey said: “Dementia can affect any one of us, and the diagnosis must not lead to people being excluded from society. The report shows that we have been able to address the lives of many people with illnesses and their loved ones through a host of concrete measures. We are also starting to develop a National Dementia Strategy, one of the main priorities for me is to be able to improve the conditions for the development of a National Dementia Strategy. For example, our goal is to create equal, good quality local contact points across the country”.

In addition, Mr Spahn commented: “People with dementia and their families are at the heart of society, it’s no longer taboo to talk about dementia.”

People with dementia and their families are at the heart of society, it’s no longer taboo to talk about dementia.”

Jens Spahn

The findings from the Alliance for People with Dementia report will be used to inform the new strategy, as well as the development of a specific office within the German Centre for Gerontology, which will be jointly funded by the two Ministries. Work to develop the country’s dementia strategy commenced on 21 January 2019, with the intention of completion and sign-off from the Federal Cabinet by the beginning of 2020.
Helga Rohra reflects on her time giving a voice to people with dementia in Europe

On 4 December 2018, Helga Rohra said goodbye to her colleagues in the European Working Group of People with Dementia (EWGPWD) after six years in the group. She spoke to us about her time in the group and the achievements she deems most important.

You were a founding member of the European Working Group of People with Dementia (EWGPWD), which was formed in October 2012 and met for the first time at the 22nd Alzheimer Europe Conference. What were your reasons for joining and what were your expectations? Were these expectations met?

Let me go back to the year 2011. I can remember the Alzheimer Europe Conference in Warsaw (Poland), at which I was invited as a speaker. Together with my colleagues from Scotland and Poland we were a kind of highlight: people with dementia at younger age (we were in our fifties at that time). The interaction with many other participants gave me confidence in our still existing abilities. At a previous Board meeting, I had already emphasised the need for people with dementia to be more involved, a point on which Jean Georges, Executive Director of Alzheimer Europe was in agreement. Alzheimer Europe was keen to involve people with dementia more in its activities (e.g. in working groups and at conferences) and we took the opportunity to share ideas on how to involve people with dementia more fully in the organisation, including on the Board. That was the point when the EWGPWD was born! A historic moment in the dementia movement!

In spring 2012, a group of people with dementia together with staff from their national Alzheimer organisations met in Glasgow to learn how a working group can function. Scotland, with its Scottish Working Group, had already some experience and were the first in Europe. What an honour to meet and learn from my friends there!

Later in 2012, the EWGPWD was founded as an Advisory Group of Alzheimer Europe. I strongly believe that the very beginning should never be forgotten as well as the first people with dementia involved. My personal motivation to join was the chance to work, to get involved at a European level, to learn from other Alzheimer organisations. The main reason was my wish to show the world that people with dementia are still valuable and to change the perception on dementia: “See us, not only our disease!” I was convinced that as part of a group and with the support...
of Alzheimer Europe we can do very valuable work in this respect.

My expectations today – after 6 years work in the group – have been more than met and I feel very honoured and happy to have been a part of amazing projects.

What did it mean to you to be the group’s first Chairperson, and could you share some things that were/have been important to you, both in your role as Chair and as a member of the group?

To become the group’s first Chairperson meant a lot to me. Like in ordinary life, this means responsibility, a need for a good command of the English language, good insights in dementia-related topics, a tough way to represent our voice at meetings.

The very sensitive difference I always felt was the balance between feelings! The members still have abilities and are passionate to contribute in projects, BUT they are fragile and tears or sadness are a part of this as well as very personal issues. I had one aim: to make everyone feel valued and feel comfortable in the group! And I know I did a good job!

I myself experienced an enormous uplift by being a Chair. I was grateful that I could carry on a part of my former life, before my diagnosis. Alzheimer Europe and the EWGPWD became a kind of family.

Dementia remains a key part of my life, a positive topic – a start of a new, a different life.

I started to write books to encourage people with dementia to LIVE, to get active in their own associations.

What would be one or two personal highlights from your two terms in this position (2012–2014 and 2014–2016)?

The EWGPWD and our achievements are simply unique! In 2012 and even some years after, very few patient organisations had patients who spoke for themselves.

We were invited as keynote speakers or partners in workshops with professionals. A highlight was our involvement as co-researchers, and being partners in many projects like INDUCT or ROADMAP – to name just a few.

Our contribution in writing papers, even books about ethical aspects or rights of people with dementia was also very important.

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 major achievement, in my mind, was our very active participation in the recognition of dementia as a disability. We helped write history in this field! Our pioneering work will be honoured by the coming generations!

I strongly believe that the members of the EWGPWD can achieve changes in their own countries, can be active partners in dementia strategies.

I am very confident that the EWGPWD will join in global projects, since we are the experts!

The group was originally formed to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia. In your view, has this been achieved?

The activities of Alzheimer Europe definitely reflect our views and focus on our priorities. I’d like to point out that the staff of Alzheimer Europe not only gives us the professional but also the sometimes needed moral support! The projects are discussed and evaluated. I always felt like a partner in a team! I have deep appreciation for this attitude! I think each member feels highly valued in his or her advisory function and there lies the uniqueness of Alzheimer Europe and our EWGPWD.

We are examples to be followed by other patient organisations!

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

Some of the main obstacles are sadly our own national organisations that we represent. I noticed in all these years that some support their members, such as Wales, Ireland and Scotland – to name some of them. By “support” I mean: showing interest in the activities we carry out, giving us the opportunity to talk, to activate people in our own countries, to include us in projects.

The political sector, especially the social and health sector could be influenced in a very positive way by giving people with dementia “power” to represent themselves.

Honestly, I tell you, I feel sad that my friends in the group are not honoured in all the countries. We are all heroes – we are all working for a better dementia world!

I am also confident that working groups of people with dementia will and have to exist in every country! I also have a dream: A person with dementia as a Member of the European Parliament!

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 carry on my work for the rights of people with dementia! My focus is on people with dementia at a younger age and their inclusion in the workplace. I am involved in projects like; “Migrants and dementia” and “Lesbian, Gay, Transgender and Bisexual (LGBT) communities and dementia”.

My current favourite is: “Care farms”, where people with dementia are both working and LIVING on the farm. And... I am writing my new book about relationships and the world of feelings in dementia.

I will of course be present at the next Alzheimer Europe Conference in The Hague with an abstract. My passion for the EWGPWD and Alzheimer Europe will go on.

Profile

Helga Rohra is an author and a dementia activist. She was a founding member of the European Working Group of People with Dementia (EWGPWD) and was the group’s first Chairperson (2012–2014 and 2014–2016). She left the group in 2018 after 6 years.

@ContactHelga
Flanders forms a working group of people with dementia

Olivier Constant, Communications Officer at the Flanders Centre of Expertise on Dementia and Hilde Lamers, Director of the Alzheimer’s League Flanders tell us about the very first working group of people with dementia to be formed in the Flemish Region (Belgium).

On 11 October 2018, the brand new ‘Flemish Working group of people with dementia’ held its first meeting. The group operates at the regional level of Flanders in Belgium.

The origins of the group

The idea grew initially from the mission of the Flemish awareness-raising campaign “Forget dementia, remember the person”, which is coordinated by the Flanders Centre of Expertise on Dementia (Expertisecentrum Dementie Vlaanderen en de regionale expertisecentra) in cooperation with the Alzheimer’s League Flanders (Alzheimer Liga Vlaanderen), the Association of Flemish cities and municipalities (Vereniging van Vlaamse Steden en Gemeenten), the Flemish Elderly Council (Vlaamse Ouderenaad) and the King Baudouin Foundation. The Flanders Centre of Expertise on Dementia started brainstorming about the idea at the beginning of 2018, together with the other plans for the new chapter of ‘Forget dementia, remember the person’. The centre joined forces with the patient and volunteer organisation, the Alzheimer’s League Flanders, to translate the ambitions for this new working group into practice. The idea of the group is also in line with the Updated Dementia Plan for Flanders 2016–2019, authored by Jo Vandeurzen, Flemish Minister for Welfare, Public Health and Family. This plan encourages us to strengthen the autonomy of people with dementia and their family caregivers.

The members

At the moment, we have five people with dementia involved, together with their family caregivers. It is our ambition to involve people with dementia in all stages of the condition, not only in the first phase of dementia and not only people who are younger than 65 years.

Goals and ambitions

Together with the members, we have defined some clear goals and ambitions for the group in Flanders: Reaching out more proactively to the media and opinion makers; meaningful involvement of people with dementia in project development, research and policy advice; valuing the expertise of people with dementia as the starting point to help reduce the stigma around dementia.

So far, so good

Since the group is brand new, we are focusing on creating an open, strong partnership between the members, as a foundation to move forward with tangible actions in 2019. We have already involved some of our members in the creation of a brand new animation movie for our awareness-raising campaign. It was released during the kick-off of the campaign on 7 January 2019. The video is available to watch at: www.onthoumens.be/in-beeld/animatiefilm-vergeet-dementie-onthou-mens

Two of our members also shared their testimonies in front of large audiences. On 25 October 2018, Paul presented at a conference on the “Reference framework for quality of life, housing and care for people with dementia” and on 30 October, Geert gave a short speech during the Special Symposium of the European Working Group of People with Dementia (EWGPWD) at the 28th Alzheimer Europe Conference (28AEC) in Barcelona.

Building a strong foundation for the future

In terms of what to tackle as a first project for the group to work on, there many ideas, which are detailed in an action plan emerging from our second meeting, which took place on 18 December 2018. A strong contender would be to produce a communication advice document for the media, to encourage them to use more respectful language and to portray dementia and people with dementia a more realistic way.

We believe that these first steps we have taken are taking us on a promising and inspiring journey that will lead to more results and an integrated vision by the end of 2019. Ensuring the sustainability of the group will be challenging, of course. It will require balancing the meaningful involvement of group members, while maintaining a balance between their personal needs and producing tangible results, but the positive energy of the true experts – the people with dementia and their loved ones – is definitely a solid basis for the future.
Geert Van Laer, a member of the European and Flemish working groups

Geert was born in a small village called Merksplas in Belgium. His father was a dairy farmer but Geert chose to study digital technology. He worked for 30 years as a telecom software engineer and spent a lot of time in Norway, Germany, Israel and China with his job. Even when he was at the head office in Antwerp, Belgium, he was working with people from all over the world.

In 2017, he received a diagnosis of early stage dementia and in 2018 he was nominated by Ligue Nationale Alzheimer Liga and became a member of the European Working Group of People with Dementia. He is also a member of the newly launched Flemish working group of people with dementia.

“Involvement of people with dementia in creating inclusive communities is essential, but I’m convinced that we need more guidance to make it work. Everybody moves at his or her own pace. A kind of procedure that describes the steps people with dementia and their loved ones can take to reach out to local policy makers would be really useful for the future.”

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Campaign website for ‘Forget dementia, remember the person’:
www.onthoumens.be
Fostering multidisciplinary exchange towards person-centred dementia care

The EU project INDEED is developing an intervention to support occupational collaboration, to improve care for people with dementia in the Danube region. Project Coordinator Alexander Kurz and Project Manager Lea Pfäffel tell us more.

As in other parts of Europe, dementia has become a major health and social challenge in the countries of the Danube region: Upstream, in countries like Germany or Austria and downstream in Bulgaria or Romania. It is estimated that at least 3 million older adults are currently living with dementia in the geographical area.

Due to increasing longevity, the number of people with dementia is predicted to rise by 50% by 2030 in Eastern and Southern Europe. At the same time, the age dependency ratio (the ratio of people aged 65 years or above relative to the population of working age) is expected to increase. The health and social systems of many countries are not optimally prepared to tackle this societal challenge.

An additional problem in the Danube region is the outward migration of skilled health workers (“care drain”) driven by economic reasons which is resulting in a lack of qualified personnel and reduced family support. A survey among experts from all 14 countries of the Danube region (9 EU Member States: Austria, Bulgaria, Czech Republic, Croatia, Germany, Hungary, Slovak Republic, Slovenia and Romania, 5 non-EU countries: Bosnia and Herzegovina, Moldova, Montenegro, Serbia and Ukraine) in 2018 identified major gaps in dementia care:

- Insufficient knowledge and skills of all professional groups involved in dementia care, including general practitioners (GPs), nurses, social workers, occupational therapists, physical therapists and pharmacists
- Poor collaboration of these professional groups and insufficient coordination of services
- Lack of dementia-specific services and facilities, particularly day centres, respite care and special care units in institutions
- Low level of public awareness of dementia and high level of stigma.

Meeting the need for multiprofessional collaboration

The initiative “Innovation for dementia in the Danube region” (INDEED) is a project supported by the European Union in the framework of the INTERREG-Danube Transnational Programme from 2018 to 2021 with funds from the European Regional Development Fund (ERDF) and the Instrument for Pre-Accession Assistance (IPA). Twenty partners from 10 countries are working together, representing academia, business, public authorities and the civil sector. An intervention is being developed, bridging the gaps mentioned above. The vision is to strengthen competences, cooperation and innovation of different institutions involved in dementia care through multidisciplinary exchange.

A triple pillar educational intervention

INDEED aims at enhancing competences and skills of key institutions involved in dementia care, comprising medical and nursing schools, professional boards and academies, public administrations, municipalities, charities, nursing home operators, business schools, commercial chambers, social enterprises and start-ups. Through capacity building at the institutional level the project adopts a top-down strategy that will lead to a broad and sustainable change of care practice for all relevant actors.

INDEED currently develops a skill-building educational intervention based on multidisciplinary exchange, addressing institutions. This intervention consists of three modules:

- An interprofessional educational and skill-building module addressing all occupational groups (CAMPUS);
- A networking tool for professions to support interprofessional and interinstitutional cooperation (CONNECT);
- Business counselling to stimulate entrepreneurial activity in the field of dementia care (COACH).

CAMPUS will provide a comprehensive overview of information that all occupations involved in dementia care should have access to. It will encompass topics such as the magnitude of dementia, the importance of timely diagnosis and the need for multiprofessional dementia management. This form of shared learning is not intended to replace but complement profession-specific education and training. Also the common knowledge base will facilitate mutual understanding and exchange.

CONNECT will portray different occupations involved in dementia care and showcase their respective services. Presenting the various contributions to dementia care and illustrating where they are offered, will be the first step towards multiprofessional person-centred dementia care.

COACH will provide real-life examples of good practices regarding business models in dementia care. Also, it will introduce basic knowledge about developing a business plan as well as about market analysis. The concept of social entrepreneurship as an innovative model in dementia care will be highlighted.

By enhancing the collaboration among occupations in dementia, the quality of care for
people with dementia will be increased, accommodating the concept of person-centred care. Activities connected to the implementation of the INDEED intervention will also contribute to the development of national dementia plans.

**Blended-learning as a new format for dementia-related skill-building in the Danube region**

There are a multitude of online courses available about dementia. Some are accessible to the general public and to informal carers, while others target professionals as part of their vocational or ongoing training. In contrast, INDEED delivers the three modules CAMPUS, CONNECT and COACH in a blended-learning concept combining a multimedia platform with traditional formats such as presentations, workshops, flyers and booklets. The INDEED consortium considers face-to-face workshops to be an essential tool to enhance cooperation, but considers online learning as a second pillar of intervention delivery. The online platform has the advantage of being accessible in rural areas where direct exchange among various professions is difficult because of long distances. In addition, the internet-based parts of the modules will include more detailed information and profession-specific learning contents from which users can select their preferences.

**Testing the strategy**

The educational and skill-building intervention will be field-tested in a series of workshops in four countries (Bulgaria, Romania, Slovakia and Slovenia). Representatives of relevant institutions as well as policy makers from the region but also from neighbouring countries will be invited to these workshops to stimulate cross-border collaboration. During the workshops, presentations will be held, printed materials will be provided and group work using the online platform will be arranged. Also, the workshops will incorporate specific region conditions. The moderation will be performed by teams consisting of one facilitator who will be active in all four countries and by another facilitator from the respective country. The workshops will be held in English.

To meet the needs and preferences of users, to align the intervention with evolving national dementia plans and to ensure its sustainability, key stakeholders are involved throughout the project. The principle of participative design has already been applied during the initial INDEED “policy assessment session” at the kick-off meeting. At this event, a group of 15 selected representatives of different institutions gave extensive insights into the current state of dementia care in the Danube region. The next participatory event will be in spring 2019 where three focus groups on dementia education will be conducted in three Danubian countries.

**Dissemination activities**

The experience gathered from the participatory events and the pilot workshops will be used to refine and complement the intervention’s content. In liaison with public authorities and policy makers the intervention will be adapted to concrete national needs. The final intervention package will be made available to all interested institutions within and outside the Danube region.

**Project partners**

**Austria:** The Brain Company, Gmunden; Vienna University of Economics and Business, Vienna.

**Bosnia and Herzegovina:** Association AiR, Sarajevo; Ministry of Health of the Federation of Bosnia and Herzegovina, Sarajevo.

**Bulgaria:** Medical University of Sofia; Bulgarian Society of Dementia, Sofia.

**Croatia:** University of Zagreb; City of Zagreb; Ministry of Health Croatia.

**Czech Republic:** National Institute of Mental Health, Prague; MediWare Medical Engineering, Prague.

**Germany:** Klinikum rechts der Isar of Technical University Munich; Bavarian State Ministry of Health and Care, Munich; Bavarian Research Alliance, Munich; German Alzheimer’s Association, Berlin.

**Hungary:** Social Cluster Association, Budapest.

**Romania:** Romanian Alzheimer Society, Bucharest.

**Slovak Republic:** Memory Center Bratislava; Slovak Medical Association, Bratislava; Slovenia: University of Ljubljana.

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www.interreg-danube.eu/approved-projects/indeed
Public opinion overwhelmingly against French decision to stop reimbursing Alzheimer’s drugs

A recent national survey in France showed an overwhelming majority of the public disagreed with the government’s decision to stop reimbursing anti-dementia drugs. Prof. Bruno Dubois spoke to us about the results of the survey and about the impact of this controversial government decision.

According to the press release published on World Alzheimer’s Day 2018 by the Société Française de Neurologie (SFN), Recherche sur Alzheimer and France Alzheimer, there is a question mark, for some, over the very existence of Alzheimer’s disease (AD) and a belief, still, that what we talk about as AD is simply the brain ageing. Survey respondents are almost unanimous (90%) in agreeing that it is indeed a very real disease, going some way to allaying fears that such a groundless belief might be widespread. Was this the main reason for doing the survey and are you pleased with this result?

There have long been schools of thought that seek to dismiss reality, even where AD is concerned. And in good faith, without doubt. Thus, some general practitioners (GPs) consider memory loss as more or less normal in later life. They do not see a reason for medicalising a condition they consider as an inevitable and more or less natural consequence of older age. One recent book, published in France, aims solely to regurgitate old arguments, declaring that AD is nothing more than a social construct.

This negationist mindset leads to the risk that older people who are ill, some of a very advanced age, may be excluded from access to care and treatments. However, just as we don’t question the treatment of cataracts or hip osteoarthritis regardless of the age at which they occur, there is no reason to deprive older patients of the care and treatment available for AD. The disease is very real: the lesions are real and are now observable in vivo: symptoms are well identified and specific. Memory problems related to AD are different from those related to ageing. Thanks to specific tests, we now know how to bring them to the fore. There is no room for confusion. It is extremely rewarding and pleasing to see that the French people, in the overwhelming majority of cases, are well aware of this.

The survey seems to show that French people have a good understanding of the impact and reach of AD and dementia. This same, well-informed population disagrees overwhelmingly (80%) with the decision made by the Ministry of Health to stop reimbursing anti-dementia drugs. Are you surprised by this level of opposition? What do you think the reasons are for such strength of feeling?

The Ministry of Health, following the recommendations of the Haute Autorité de Santé (HAS), made the decision to stop the reimbursement of anti-Alzheimer drugs, despite evidence of their modest but irrefutable efficacy, proven in double-blind studies. It is interesting to see that the French population, again in its very large majority, disagrees with the decision. This does not surprise me, because it is consistent with what we, specialised doctors, observe in our daily practice.

There is a growing number of cases where patients notice worsening of their symptoms after they stop taking these medications. Others, meanwhile, have taken the decision to continue their course of treatment despite having to pay out of their own pocket. This can cause financial problems, particularly among retired people. This ministerial decision is very unfortunate and, to put it bluntly, incomprehensible.

“This ministerial decision is very unfortunate and, to put it bluntly, incomprehensible.”

There have been a number of groundless media claims that anti-dementia drugs do “more harm than good” (although, reassuringly, these survey results show that public opinion in France has not been swayed by such sensationalist reporting). Can you give us your assessment of the efficacy of these drugs and the reality of the benefit-harm ratio?

These drugs have shown real efficacy on the symptoms of patients. Moreover, drugs do not obtain market authorisation without clear proof of their benefits. Their efficacy has been demonstrated in studies, initially conducted over 6 months, and later confirmed in longer-term studies. They have also shown the ability of these treatments to delay institutionalisation and to reduce caregiver-burden. The DOMINO study found that the number of entries into institutions was higher among patients who had discontinued treatment than in those who continued. Moreover, stopping treatment leads to the brutal exacerbation of symptoms.

Pharmacovigilance has not shown any serious adverse effects since these drugs were put on the market, 20 years ago. All you have to do is respect the doses and contraindications, as for any medication. Overall, the benefit / risk ratio remains favourable. This is also the finding of the National Institute for Health and Care Excellence (NICE) in the United Kingdom, where there is little inclination to spend public money senselessly.

Aside from the emotional and financial impact on persons living with dementia who are currently taking these drugs with positive results, are there any other negative consequences of stopping reimbursement? Will it have an impact on early diagnosis rates, or on research, for example?
It cannot be ruled out that this decision may, unfortunately, have an impact on early diagnosis and research. On that subject, I would look to the thesis of JF Ballenger, a historian of science. In his article “Progress in the history of Alzheimer’s disease: the importance of context”, he points out that putting dementia and senility in the same box would have resulted in abandoning all research into the disease for half a century, between the 1920s and 1970s. We can only hope that this new resurgence of obscurantist theories will not have that effect…

Has the SFN any plans for further action in this area?

At a time when some are questioning the very existence of the disease and the effect of anti-Alzheimer drugs, the SFN, as a scholarly society, conducted this survey because it deemed it important to highlight its concerns and remind people that AD is indeed a disease of the nervous system. It corresponds to a specific and now well-established pathology; it results from very real lesions, which are now observable during patients’ lives; it causes well-identified symptoms.

Finally, SFN felt that in the current context, it ought to reiterate that the only constructive response to this public health issue, going forward, is to provide people with dementia with the best possible support and to further our understanding of the brain lesions, their causes and how to stop them.

Profile

Prof. Bruno Dubois is a professor of Neurology at Sorbonne Université and President of the Société Française de Neurologie (SFN).

www.sf-neuro.org

Graphic shows high percentages of French people (under and over 60) who disagree with their government’s decision to stop reimbursing anti-dementia drugs.

“Stopping treatment leads to the brutal exacerbation of symptoms.”
A look behind the headlines: The promise and reality of AI predicting AD

Alzheimer Europe interviewed Prof. Craig Ritchie and Dr Samuel Danso, from the Centre for Dementia Prevention (Edinburgh, Scotland), about recent headlines suggesting Artificial Intelligence (AI) could be used to “spot Alzheimer’s” years earlier than current diagnosis methods allow.

For the purposes of this article, Prof. Ritchie and Dr Danso specifically referred to an article in the Telegraph newspaper, titled “Neck scans, gene tests and AI apps: the race to ‘catch’ dementia early”, published 18 November 2018.

Were the headlines right or were they misleading in some way?

This Telegraph article mentions three recent studies that report the application of AI technology in predicting the developments of Alzheimer’s dementia by three separate research groups.

Study 1 looked at using advanced AI technology called deep learning to predict Alzheimer’s dementia based on features obtained from positron emission tomography (PET) scans.

Study 2 looked at how AI technology could be used to predict clinical trajectories of Alzheimer’s dementia and in people in earlier stages of Alzheimer’s disease, who have what is commonly referred to as prodromal dementia. Their aim is to one day help clinicians make important decisions on the type and frequency of assessment, based on features obtained from both clinical data and computerised tomography (CT) scans of the brain. For example, patients that are predicted to be in a ‘fast-decline’ category may be recommended for close monitoring through frequent assessment and implementation of preventive interventions compared to patients predicted to be in a ‘slow-decline’ category.

Study 3 (www.joingamechanger.org) sought to employ AI powered technology through a smartphone app called Mezurio to collect data from participants diverse populations to help understand what healthy cognition is. The data collected from participants include activities that require them to use memory, thinking and learning skills during interaction with the app. Based on review of the above studies and other similar published initiatives that are looking at application of AI technologies within the dementia domain, the headline appropriately captures and conveys an important and exciting series of initiatives which genuinely may have impact not only for research but also clinical practice. AI correctly applied may one day play an important role to predict onset and progression of Alzheimer’s disease.

How important is this story/study for furthering dementia research? Should we be excited?

There are numerous benefits of employing AI technology in dementia research. This includes early detection of brain disease that may later lead to dementia.

The ability to predict an individual’s likelihood of progression within a given timeframe provides researchers the ability to recruit participants into clinical trials accurately and effectively. The second study is a major contribution to the data driven approaches to this potentially effective recruitment process.

There are numerous benefits of employing AI technology in dementia research. This includes early detection of brain disease that may later lead to dementia.

What might be the impact of this story/study in the scientific community?

AI technology has two components: the algorithm and the data that serve as input. Study 1 and 2 propose novel algorithm frameworks that can be further developed and refined. It was interesting to see how the proposed algorithms performed against the already known algorithms such as Support Vector Machine and Random Forest when applied to the tasks described in particular and the dementia domain in general.
This approach introduces robust and objective assessment of participants, which can feed into AI algorithms in real time at large scale to be deployed for identification in the community through screening with this technology for people at risk of dementia and monitoring progression of brain disease.

**What are the next steps?**

Even though the studies described in the article have the potential to be employed within the dementia research community, more work needs to be done before they are ready for prime time in the clinic or on your smartphone. It is a well-known issue that AI algorithms tend to suffer from generalisation problems.

Prediction accuracy of the algorithms does not perform as reported when applied to a different dataset. This is particularly true when the data used to develop the algorithms are inadequate (they may be small or not have the ‘right’ data variables measured accurately). For instance the studies reported in the newspaper article have relatively small sample sizes.

Study 1 used only 48 samples of PET scans to develop the deep learning algorithm and Study 2 used only 69 samples of CT and clinical data to develop the trajectory prediction model. One day we will need datasets of several thousands to develop really accurate models. The more individuals participate in a project of this nature, the more likely the results will be applicable to a broad range of individuals. In a small sample the results may not be robust enough to produce similar performance on another dataset. Another reason for the need to have further validation of these studies is the variable nature of how we define dementia as well as the different types of brain disease that lead to a range of different ‘dementias’.

This introduces another level of complexity from a computational modelling perspective and makes results less easily implemented into the clinical practice. For example, there is currently overreliance on cognitive decline as the outcome of interest on dementia, but this could also be due to depression and is also only one way to measure the consequences of brain disease. Would the models that predict decline in memory also predict advancement of brain disease and which is more relevant and at which stage of the illness? Furthermore, as it has been established that brain diseases that lead ultimately to dementia start much earlier in life, it is important to validate these algorithms in much younger populations.

In the listed studies, older populations (average ages >70 years) were used in developing the algorithms. Planned analysis in fantastic databases/studies where research participants are really well-characterised could be used to validate and improve upon these algorithms through their development in substantially larger numbers of people at a much earlier stage of brain disease. Some examples of such databases/studies would be the PREVENT Dementia (www.preventdementia.co.uk) and ALFA Project as well as the European Prevention of Alzheimer’s Dementia (EPAD) (www.ep-ad.org) programme.

AI will yield amazing results and the headline does herald the coming together of a computational approach and better and larger datasets giving the individual and the clinician the most important factor in making the right decision for themselves and for their patients: knowledge.

**Profile**

Prof. Craig Ritchie is a Professor of the Psychiatry of Ageing, and director at Edinburgh Dementia Prevention, the University of Edinburgh. He is also a visiting Professor at Imperial College, London. Prof Ritchie leads and the Chief Investigator of numerous dementia research projects and these include the EPAD, PREVENT Dementia Programme, and the Scottish Dementia Informatics Partnership. He has authored several publications in the area of dementia research and currently chairs the Board of the United Kingdom Dementia Platform Programme.

**Profile**

Dr Samuel Danso is a Researcher & Data Scientist at Edinburgh Dementia Prevention, the University of Edinburgh, and a Fellow at EPAD Academy. He holds a PhD in Artificial Intelligence with special research interest in application of AI approaches and technologies to dementia research. Dr Danso plays a key role in several dementia research projects – EPAD, PREVENT Dementia Programme, and the Scottish Dementia Informatics Partnership.

**Profile**

The University of Edinburgh’s Centre for Dementia Prevention combines research in science, medicine and social sciences to lead global efforts in preventing dementia. 

[www.centrefordementiaprevention.com](http://www.centrefordementiaprevention.com)
Alzheimer Europe Conference held in Barcelona under the banner “Making dementia a European priority”

The 28th Alzheimer Europe Conference “Making dementia a European priority” was held under the Honorary Patronage of Her Majesty Queen Sofia of Spain. More than 800 participants from 46 countries participated.

The 28th Alzheimer Europe Conference (#28AEC) was formally opened on the evening of 29 October 2018 by Iva Holmerová, Chairperson of Alzheimer Europe (AE). Ms Holmerová thanked HRH Queen Sofia for her Patronage and extended a special welcome to the 35 people with dementia attending the conference, as well as their supporters. Ms Holmerová has been involved in the dementia movement for many years, during which, she shared that her “purely” professional view on dementia had changed due to meetings with people with dementia and caregivers, as well as through her close personal insight into dementia, with her mother and her mother’s partner having the condition. She said she now believed that we should broaden our focus, which has been mainly on diagnosis, pharmacotherapy, interventions and management. The individual needs and preferences of people with dementia and their families should be considered and respected, she emphasised, and these needs and preferences must translate into clinical and practical thinking and acting.

Following Ms Holmerová, Cheles Cantabrana, Chairperson of the Confederación Española de Alzheimer (CEAFA), Noemí Martínez, Vice-Chairperson of Fundación Alzheimer España (FAE), Santiago Marimón Suñol, who is living with dementia, and Gemma Tarafa, Commissioner for Health and Functional Diversity for the City of Barcelona, also addressed the delegates.

**Putting dementia in the spotlight in Spain**

Ms Cantabrana (CEAFA) thanked Alzheimer Europe for helping to put dementia in the spotlight in Spain by holding its conference in Barcelona. She emphasised the importance of Spain taking the final step to approve its national dementia strategy, the creation of which has been one of the focal points for her organisation in recent years. She implored representatives of the Spanish authorities in attendance to use the experiences of other countries present to help them move forward.

**Focusing on early diagnosis rates**

Ms Martínez (FAE) highlighted some positive changes in recent years, for people with dementia and their carers, with a huge increase in the information, training and scientific knowledge available to them. She highlighted that there is more participation from everyone concerned (institutions, self-help movements, and pharma and tech companies, among others), whilst also noting that there are too many differences across
Europe with regards the length of time from diagnosis to end-of-life. In the immediate future, FAE will be focusing on improving early diagnosis rates, as well as helping patients and carers access new technologies and training, helping forge better links between professionals and families and putting more pressure on the relevant authorities to help implement everyday solutions.

**Living with dementia in Spain**

Mr Marimón Suñol, representing the Spanish Working group of people with dementia (AFAD), opened his speech by saying how truly honoured he was to speak on behalf of people living with dementia. He informed delegates about two initiatives he and his fellow AFAD members are currently involved in: The first involves giving input on and supporting the upcoming national dementia plan for Spain, and the second is a project trying to establish a network of cognitive stimulation activities. He also paid homage to Pasqual Maragall, former Mayor of Barcelona and President of the Generalitat de Catalunya, who is himself living with dementia. The Pasqual Maragall Foundation in Barcelona funds research on Alzheimer’s disease and dementia. Mr Marimón Suñol ended with a heartfelt thank you to everyone at the conference for the work they do to advance research and care in the dementia field.

**Tackling the challenge of an ageing population**

Commissioner Tarafa invited delegates not only to enjoy the conference, but also to explore the lively city of Barcelona. She shared conclusions from a recent meeting of stakeholders, which found that the ageing of the population is one of the two main challenges facing the City of Barcelona in the coming decades (with the other being the impact of pollution on health). An ageing population means an increasing number of people affected by dementia, she pointed out, and the City of Barcelona will take a three-pronged approach to tackling this challenge: firstly, through awareness-raising; secondly, by supporting and furthering research into dementia prevention; and finally, ensuring that better support is available for carers. In closing, Ms Tarafa drew the audience’s attention to the “4000 bubbles” campaign – an art installation to create a dialogue around dementia – timed to coincide with the Alzheimer Europe Conference.

**Collaborating to overcome the challenges presented by dementia prevention**

In his keynote presentation “Will we be able to prevent Alzheimer’s disease?” Dr José Luis Molinuevo from BarcelonaBeta Brain Research Center gave an overview of the challenges and opportunities regarding the prevention of Alzheimer’s disease (AD). He expressed the rationale behind preventing AD and the reason why prevention may be key to tackling it. However, he stressed that this is far from easy and there are many challenges along the way.

Dr Molinuevo commented: “Although the advent of biomarkers does allow us to identify AD in vivo through biomarkers that are proxies of pathology, and improved trials design is allowing us to test new pathways in a more efficient way, defeating AD is still a challenge that will require all of us working together to find a solution”.

Following Dr Molinuevo’s lecture, delegates enjoyed a lively welcome reception in the foyer of the Barceló Sants Hotel, where they were treated to a fusion of Flamenco and Afro-Cuban music played by the group “Sabor de Gracia”.

While the advent of biomarkers allows us to identify AD in vivo and improvements in trial designs mean we can test new pathways more efficiently, defeating AD remains a challenge that requires a huge collaborative effort.”

José Luis Molinuevo
Alzheimer Europe Conference plenaries focus on policy, human rights, care and research

The 4 plenary sessions at the 28th Alzheimer Europe Conference “Making dementia a European priority” took place on 30–31 October 2018 and focused on dementia as a policy priority, the importance of a human rights-based approach to dementia and disability, dementia as a care priority and dementia as a research priority.

Dementia as a policy priority

The first plenary session on “Dementia as a policy priority” was chaired by Jesús Rodrígog (Spain) and opened with the first of four “Meet the researchers of tomorrow” sessions. Anja Leist, Associate Professor at the University of Luxembourg, presented the World Young Leaders in Dementia (WYLD) network, which brings together young professionals in the field of dementia, supporting the work of the World Dementia Council. The WYLD consists of over 250 members from 30 countries around the world and ages range from 22–40. Its priorities are to facilitate professional careers in dementia by offering training and mentoring, to facilitate the uptake of new technologies to improve quality of life of persons with dementia and their families and to increase awareness and fight stigma around dementia.

Carmen Orte, Director General of IMSERSO (Instituto de Mayores y Servicios Sociales) presented “Dementia as a health and social priority in Spain”. Ms Orte highlighted the importance of putting our focus where it is most needed, where dementia and specifically Alzheimer’s disease is concerned: on reducing its impact; on improving quality of life for people with dementia and their family caregivers and on ensuring they can fully exercise their rights; on ensuring people with dementia can continue to live in their chosen environment for as long as possible; promoting maximum autonomy and participation by means of involving wider society in our response to the challenge posed by dementia. She also stressed the need to put a
STOPLIGHT ON 28AEC

Dementia in Europe

We need to put a stop to stigmatising behaviour towards people with dementia. Awareness and consciousness-raising, valuing caregivers more highly, and more research, innovation and knowledge-sharing will help achieve this.

Carmen Orte

Prof. John Gallacher, Project Co-ordinator of the IMI ROADMAP project (Real world Outcomes across the Alzheimer’s Disease spectrum for better care: Multi-modal data Access Platform), closed this engaging first plenary session. He shared the work done by the project so far: The ROADMAP project has demonstrated the ability of academic, industry, patients and regulatory partners to work together on a highly complex, widely distributed, and tightly time-constrained project; established a broad-based and evidence based consensus on the priority outcomes for dementia treatment pathways; developed a comprehensive database of available European real world data; demonstrated that the current evidence base is inadequate for disease progression modelling and detailed health economic evaluation; and has made a strong case for the collection of new data that is intentionally designed to enable early detection and disease progression modelling.

Dementia as a human rights priority

The second plenary session focused on “Dementia as a human rights priority” and was chaired by Charles Scerri (Malta). The session opened with the second “Meet the researchers of tomorrow” session, delivered by Stina Saunders, a fellow at the IMI EPAD project (European Prevention of Alzheimer’s Dementia) and a doctoral candidate at the University of Edinburgh. Her talk focused on engaging research participants as collaborators working towards a common goal with the study team. The EPAD study has set up the EPAD Participant Panel in order to learn from the experience of research participants, provide participants an on-going active voice in the project and incorporate participants’ input.

Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD), took the floor next, to talk about promoting a human rights-based approach to dementia through the active involvement of people with dementia. This is a cause very close to her heart, as a person living with dementia who advocates for the rights of people with dementia, and having been a Rights and Social Justice Campaigner all her life. “Many people living with dementia are denied their human rights from the time of diagnosis. As they live with the disease they navigate systems and structures which are not person centred and rights based. As a result, either deliberately or by omission their human rights are denied”, said Ms Rochford-Brennan. Human rights violations include the lack of statutory rights to homecare the inappropriate prescribing of Psychotropic medicines and the inability of persons living with dementia to be active participants in their community. People living with dementia must be actively involved in all aspects of the disease.

From research to healthcare, legislation to awareness, the lived experience must be valued and have the power to influence. Good practice for involving people with dementia...
includes appropriate supports, a non tokenistic approach and a value placed on experts by experience. The members of the EWG-PWD, are strong advocates of PPI (patient and public involvement) and believe co-creation and robust collaboration are the only way to ensure that the human rights of persons living with dementia are a research priority. “Human rights can be a theoretical, abstract concept that for some people living with dementia seems far removed from their daily reality. Quality engagement with just such people will lead to the human rights of many more people living with dementia being met”, she concluded.

Dr Fernando Vicente, advisor to the General Directorate of the Institute of Older People and Social Services (IMSERSO) of the Ministry of Health, Social Services and Equality, was up next. Addressing the room in Spanish (simultaneously translated into English), Dr Vicente spoke about Human Rights in Spanish health and social legislation: In the discussion about ageing, there has been a heated debate at national and international level about whether the existence of specific legal instruments on the rights of older persons and their protection is necessary. Reasons for not having such instruments include the fact that people have rights because they are human beings regardless of age, gender, language, sexual orientation, capacity, abilities, etc. and instruments and specific norms for the protection of the older people already exist (e.g. International Human Rights Conventions of the UN, Charter of Fundamental Rights of the EU of 2010, Constitution of 1978, Civil Code, Penal Code). Nevertheless, the existence of sectoral legal norms at international, national and regional level (in the case of Spain) aimed at the protection of groups that are particularly vulnerable, is a reality of the political action that is appropriate to the challenges posed by the ageing of the population. This constitutes a great challenge of governance in Spain and hinders the adoption of measures to mobilise action, he concluded.

Dr Dianne Gove, Director for Projects at Alzheimer Europe, gave delegates an overview of the organisation’s work on dementia and disability. In 2017, Alzheimer Europe set up a working group of experts on dementia, disability, ethics, mental health legislation, anthropology, policy and psychology, which worked closely with members of the EWG-PWD. Together, they explored possible implications for ethics, policy and practice of recognising dementia as a disability. Thinking about how people with dementia might experience and feel about disability, it is important to emphasise that disability, like dementia, is not a person’s sole identity. People have multiple, intersecting and overlapping identities. Dianne stated that whilst overall, there may be ethical, practice and policy benefits of viewing dementia as a disability, none of these potential benefits should require a particular person with dementia to identify with disability against his/her wishes, and emphasised the need to recognise and respect difference and individual choice.

Dr Karen Watchman, Senior Lecturer in the Faculty of Health Sciences and Sport at the University of Stirling, closed the second plenary session with her talk on dementia and

Plenary 2 speaker panel (left to right) Karen Watchman, Stina Saunders, Dianne Gove, Charles Scerri, Helen Rochford-Brennan, Fernando Vicente
intellectual disability. Dr Watchman told delegates that, whilst countries across Europe are at different stages in their support of people with an intellectual disability, longer life expectancy of people with Down syndrome means a rise in the incidence of early onset dementia, with at least 1 in 3 people with Down syndrome being diagnosed in their 50s or 60s. Older families are facing the multiple jeopardy of caring for their relative with an intellectual disability who is ageing, and has a diagnosis of dementia. This is often at a time when they are facing their own ill health, she pointed out.

Increased knowledge and awareness among support staff in health and social care sectors/NGOs can lead to greater understanding of the impact of individualised non-drug supports for people with an intellectual disability and dementia, including the potential for a reduction in medication. Improvement is also needed in the area of diagnosis and post-diagnostic support, for residents with intellectual disability who are diagnosed with dementia. A longer-term approach is needed to support this ageing population, which takes into account the perspective of the person with intellectual disabilities. “By valuing the perspectives of people with an intellectual disability and dementia, we reinforce the importance of ensuring that best-practice for people with dementia also applies to people with an intellectual disability. This includes a timely diagnosis which is shared appropriately, individualised post-diagnostic support, and the need to meaningfully include the perspective of persons with intellectual disability in decisions that affect them”, Dr Watchman concluded.

**Dementia as a care priority**

The third plenary session “Dementia as a care priority” was chaired by Myrra Vernooij-Dassen (Netherlands) and opened with the third “Meet the researchers of tomorrow” session, with Sébastien Libert, a PhD student based at University College London, and part of the Interdisciplinary Network on Dementia Using Current Technologies (INDUCT). He argued that, with the increasing promotion of an active and productive later life in western societies, there is a growing discomfort and anxiety among parts of the ageing population, around thinking about decline and dementia. This cultural anxiety also influences the development of assistive technologies promoting self-management and activity in dementia, which results in the potential cognitive decline associated with the progression of dementia not being primarily addressed in the design of many of these technologies. It is therefore important to consider how the progression of dementia affects people’s experiences with such technologies, often developed to help with early to moderate dementia, he concluded.

“We need to address traditional forms of outcome assessment, which are often based in a deficit model rather than one which promotes living well with dementia, i.e. what can no longer be achieved rather than what can.”

**Gail Mountain**
Gail Mountain, Professor of Applied Dementia Research and Director of the Centre for Applied Dementia Research at the University of Bradford used her presentation to urge delegates to work together to reconsider the appropriateness of commonly-used outcome measures in dementia practice and research. The issues she stated as needing to be addressed are: Traditional forms of outcome assessment can be based in a deficit model rather than one which promotes living well with dementia – what can no longer be achieved rather than what can; The constructs being measured can contribute towards the deficit model – what about ability to self-manage and retain resilience rather than ADL?; The majority of traditional forms of assessment require recall; a challenge for those with cognitive deficit. Prof. Mountain suggested a radical rethink regarding what should be asked and how, including the role of new technology in creating solutions to this problem.

Marjolein de Vugt, professor of psychosocial innovations in dementia at the Mental Health and Neurosciences research school, Maastricht University presented the ‘Partner in Balance’ programme. She noted that existing e-health interventions for caregivers of people with dementia are mainly aimed at dealing with dementia-related problems, but may not fit the needs of informal caregivers of persons at an early stage of the disease process. The programme she presented aims to respond to this unmet need. It is a blended care intervention, developed specifically with and for informal caregivers of people with dementia in the early stages and she was pleased to announce that a randomised, controlled trial has already had positive results in the areas of self-efficacy, experienced control and quality-of-life.

Manuel Martín-Carrasco, Medical Director of the Father Menni Psychiatric Clinic of Pamplona, spoke to delegates about reducing the use of antipsychotics in residential and nursing homes. The fact that many people with dementia are living in long-term care facilities, leads to a high rate of psychiatric symptoms and behavioural problems, said Dr Martín-Carrasco. A high rate of psychopharmacological treatments, in particular antipsychotics and benzodiazepines are used, as a result and these drugs are associated with an array of deleterious effects, including an increase in mortality. Various methods have been tried, to reduce the use of antipsychotics in nursing homes, the most successful of which, overall, seems to be the implementation of sustained training programmes, leading to a change in the culture in the facilities themselves.

Marjina Roes, Chair of Nursing Science and Health Care Research at the Department for Nursing Science / Faculty for Health, University of Witten/Herdecke closed this plenary session with a presentation on “fostering and sustaining relationships with people with dementia”. She emphasised that maintaining existing relationships and making and sustaining new connections are of paramount importance in ensuring quality-of-life for people with dementia, and this, according to people living with the condition themselves. This is why relationships are such a fundamental component in person-centred care. 

Martina Roes

“Maintaining relationships and making connections are of paramount importance in ensuring quality-of-life for people with dementia, according to people living with the condition. This is why relationships are such a fundamental component in person-centred care.”

Dementia as a research priority

The last plenary session focused on “Dementia as a research priority” and was chaired by José Manuel Ribera Casado (Spain). It began with the fourth and final “Meet the researchers of tomorrow” session, presented by Isadora Lopes Alves, who is currently doing her postdoctoral research for the IMI AMYPAD project (Amyloid Imaging to Prevent Alzheimer’s Disease) at the VUMc, Amsterdam. The AMYPAD Consortium involves 9 centres across Europe and aims to examine the value of amyloid PET imaging in two clinical studies recruiting up to 2,900 individuals. Expanding findings from other studies on clinical utility of amyloid PET imaging (ABIDE and IDEAS), the AMYPAD Diagnostic Study is looking to understand for whom and when this technique is valuable, and whether its optimal use is cost-effective in clinical routine. In combination with EPAD, the AMYPAD Prospective Study is using amyloid PET imaging to improve the determination of an individual’s risk of developing dementia, and will provide crucial technical insights into how current and future secondary prevention trials can improve participant selection and measurement of treatment effect using amyloid PET.

Next, Maria Isabel Gonzalez Ingelmo, Managing Director of the National Reference Centre for Alzheimer’s and Dementia Care of the Institute for Older Persons and Social Services (IMSERSO), under the auspices of the Spanish Government, informed delegates that her organisation is committed to promoting research into non-pharmacological therapies, through networking and transferring knowledge. She spoke about the importance of social and health care research in the field of Alzheimer’s disease (AD) and other dementias. This area of research pursues the development of evidence-based interventions that are able to improve the quality-of-life of people with dementia and their families. Ms Gonzalez Ingelmo emphasised that clinical research and social and health care research are equally important and must work hand in hand, to achieve the best results for everyone concerned.

Mercè Boada, Founder and medical director of Fundació ACE, used her session to stress the important role EU research collaborations can play in helping to improve the diagnosis of AD. Identifying ways to improve early diagnosis of AD and changing the current perception that dementia is part of the normal ageing process are on the global agenda. European cooperation in projects like MOPEAD or ADAPTED are a great opportunity to establish strategies focused on increasing knowledge and awareness. “Health policymakers, stakeholders, national Alzheimer associations and academic institutions should collaborate to improve our healthcare systems, by training primary care practitioners and other healthcare professionals cross Europe working in the field of neurodegenerative diseases. It is crucial to find biomarkers that are assumable for our
healthcare systems as well as less invasive for people affected”, concluded Dr Boada.

Next up to the podium was Philippe Amouyel, Professor of Epidemiology and Public Health at the University Hospital of Lille, with a presentation on the genetics of Alzheimer’s disease (AD): AD occurrence, as with many chronic diseases, results from the interaction between environmental factors and an individual susceptibility. In less than 1% of AD cases, mostly early onset forms, genomics has been able to identify several causing genes, and set the basis of the amyloid cascade model. In the sporadic forms of AD, the most common, genomics research, based on an agnostic screening of the genome, has allowed scientists to identify new pathophysiological pathways, improving understanding of the molecular processes involved in AD.

Over the past 10 years, the exponential progress made in the deciphering of the genome have meant that more than 30 regions of the genome, associated with an increased or decreased risk of AD in these late-onset forms, have been identified. Still, Prof. Amouyel pointed out that almost half of the heritability of AD remains to be identified. Genetics, he concluded, will play a pivotal role in general prevention, identification of disruptive treatments and care. Due to its predictive role, genetics has a major influence on prevention, pre-symptomatic and early diagnoses of dementia. This deserves careful discussion, particularly linked to ethical considerations.

The final speaker at plenary 4 was Professor Clive Ballard, who is part of a growing team of dementia researchers at the University of Exeter Medical School. His presentation looked at pharmacological options for the treatment of behavioural symptoms of dementia and specifically at the recent international Delphi consensus paper. The paper brings together leaders in the field to update guidance based on latest evidence. It advises that drug treatments should only be used as a last resort for the treatment of agitation, and highlights the need for more work focusing on specific non-pharmacological interventions for psychosis most universally experienced by people with dementia. Non-drug approaches include identifying underlying causes, training caregivers, making environmental adaptations, implementing person-centred care, and devising a programme of tailored activities.

There is an emergence of promising research, focusing on new pharmacological treatments, including analgesics, citalopram, pimavanserin and dextromethorphan; and we are likely to see a significant advance in the treatment of Behavioural and Psychological Symptoms in people with Dementia over the next 5 years. Prof. Ballard summarised the study’s results, saying: “We know that antipsychotics and sleeping tablets can all be highly damaging to people with dementia. The headline here is that sedating elderly, frail people with dementia is likely to cause them harm and should be avoided if at all possible. Our paper brings together the latest evidence in this field and advises professionals to try non-drug approaches where possible and highlights emerging pharmacological therapies which may provide safer and more effective approaches to treatment in the future.”
Snapshots of #28AEC

Cheles Cantabrana, CEAFA, addresses delegates during the Opening Ceremony

A sunny backdrop to another exciting and packed conference

Noemí Martínez speaks on behalf of Fundación Alzheimer España, at the Opening Ceremony

Helen Rochford-Brennan stresses the importance of a rights-based approach to dementia

Sébastien Libert presents one of the meet the researchers of tomorrow sessions

José Luis Molinuevo delivers the keynote lecture

Chris Roberts shares his lived experience of dementia during the EWGPWD Special Symposium

Spanish sessions were simultaneously translated to English and vice-versa

Networking between sessions helps forge and reinforce vital international collaboration

EWGPWD member Idalina Aguiar (left) with her daughter and carer, Nélida (right)

John Gallacher shares the success of the ROADMAP project during its two years

Some of the 175 posters presented at 28AEC
European Working Group of People with Dementia begins fourth term of office

The working group began its fourth two-year term of office at a meeting held on 28 October 2018 in Barcelona, prior to the 28th Alzheimer Europe Conference.

Prior to the conference, members of the European Working Group of People with Dementia (EWGPWD) met to prepare for their involvement in the programme, including the Special Symposium “I have dementia and life goes on”, which took place on 30 October 2018.

The members

The EWGPWD for 2018–2020 is composed of the following 13 members, including four new members, welcomed by the group at this pre-conference meeting:

- Helen Rochford-Brennan, Ireland (Chairperson)
- Chris Roberts, UK – England; NI and Wales (Vice-Chairperson)
- Idalina Aguiar, Portugal
- Stefan Eriksson, Sweden (new)
- Tomaž Grižnič, Slovenia
- Amela Hajrić, Bosnia & Herzegovina
- Carol Hargreaves, UK – Scotland
- Bernd Heise, Germany (new)
- Miha Kastelic, Czech Republic (new)
- Petri Lampinen, Finland
- Thomas Maurer, Switzerland
- Angela Pototschnigg, Austria (new)
- Geert Van Laer, Belgium.

Symposium “I have dementia and life goes on”

One of the highlights of the conference was a symposium organised by the group and, chaired by Helen Rochford-Brennan and moderated by Chris Roberts.

The entire group participated and each member shared a few words about themselves and their lived experience. Finnish member Petri Lampinen then gave a speech about his experience of receiving a diagnosis of frontotemporal dementia, the impact it had on him and his family and his approach to living life to the fullest. Chris Roberts translated his words to English, for the audience.

As every year, the EWGPWD Symposium was incredibly popular and there was lively audience participation, during the closing Q&A session.

Carers and supporters of the group’s members joined them on the stage and at the end of the symposium, they made the statement: “Many voices together make our voice stronger”.

Departing members

Former EWGPWD members Nina Baláčková (Czech Republic) and Helga Rohra (Germany) also attended the pre-conference meeting and participated in the symposium but have now left the group. Both were founding members of the EWGPWD, having joined in October 2012. Ms Baláčková was also Vice-Chairperson in 2013–2014 and Ms Rohra was the group’s first Chairperson (2012–2014, 2014–2016).

Alzheimer Europe and the EWGPWD wish to thank both of them for their important and positive contributions, as well as thanking their friends and family members, for their support.

The European Working Group of People with Dementia was set up by Alzheimer Europe in 2012. It is composed entirely of people with dementia, nominated by their national Alzheimer associations. They work to ensure that the activities of Alzheimer Europe reflect the priorities and views of people with dementia.
Congratulations to the winners of the poster awards!

The Alzheimer Europe Foundation is pleased to present the winners of the poster competition, as voted by delegates at 28AEC.

The Alzheimer Europe Foundation is pleased to present the winners of the 28AEC poster competition, as voted by delegates. The winners were awarded EUR 750 and the runners-up were awarded EUR 250.

WINNER: Luisa Bartorelli (Italy), “The new Alzheimer village of the Fondazione Roma: A positive approach for people with dementia”

This poster introduces Villaggio Emanuele (named after its founder), a new “Alzheimer village” in Rome. It aims to offer residents with dementia an environment that is as close to “normal life” as possible, whilst ensuring their safety and wellbeing. The Village, with its streets and piazzas, is a structure where residents can move around independently in “spazi di liberta”. It is open to the outside world and the poster authors emphasise the importance of involving neighbours and the local community, to contribute to the concept of a dementia friendly community.

WINNER: Bie Hinnekint (Belgium), “CasAperta, music and arts café by people with dementia and their carers”

This poster introduces the CasAperta project in Ghent. CasAperta is a music and arts café and a support-group, founded in 2016. The aim is for people with dementia and their carers to have new experiences together, enjoy music and arts, make friends and by participating spread the message that “Living well with dementia is possible”. Over 25 pairs from around the greater Ghent area are participating.

CasAperta Music-Salon is a new element of the project, developed in 2018. It takes place across six Sunday afternoons in the Quatre Mains music café, where classical music is performed by two young musicians from the Royal Academy of Fine Arts in Ghent (HoGent). It is extremely popular and is usually fully-booked.

CasAperta believes in the creative capacities of people with dementia and the use of imagination to branch out, finding new ways to do things, rather than holding on to activities people used to enjoy. The emphasis is on using creativity and abilities in the here and now.

RUNNER-UP: Nélida Aguiar (Portugal), “Perpetuating memories”

Nélida Aguiar’s mother, Idalina Aguiar has Alzheimer’s dementia. Her poster looks at the importance of living well with dementia, which she says can be done by “maintaining the bonds that unite us with the past, while providing the best comfort in the present and accepting the uncertainty of the future.”

For Ms Aguiar, living well with dementia is: integration, acceptance, adapting, reinventing the day-to-day, preserving the memory for as long as possible, working hard on understanding the will of the person with dementia, listening to their voice and valuing their opinion. It is of great importance to realise that a diagnosis of dementia is not only about the impact of the disease on the person, but rather its impact on the whole family, she says. The capacity to adapt to change is fundamental in uniting and strengthening family ties and it is important to live with love, respect for the individual and by remaining integrated in society as much as possible.

RUNNER-UP: Lucas Paletta (Austria), “PLAYTIME: Motivation, emotion and assessment in serious games for dementia intervention”

The effect of serious games for cognitive stimulation of people with dementia has been thoroughly tackled via several avenues of intervention. The team responsible for this poster argues, however, that the impact of motivational support and emotion requires more investigation in the context of serious games and dementia. Their poster presents the first results of the European project PLAYTIME and looks at future trajectories in the field:

1. Indicators for cognitive assessment were implemented using web camera based eye tracking.
2. Capacity for physical activities and balance were assessed with a wearable sensor-based motion test.
3. Psycho-social aspects were analysed from a newly developed serious game component using decision-making in role play. It also presents results from the first field study about the usability of these innovative components.

Sharing the winnings

The winners have all made the generous decision to donate their prize money or use it for charitable actions:

- Luisa Bartorelli has donated hers to Alzheimer Uniti Roma where it will be used to help people with dementia and their families in Italy.
- Bie Hinnekint will use hers to organise further CasAperta music salons.
- Lucas Paletta gave his to the Sozialverein Deutschlandsberg, an organisation that works with people with dementia living at home, in remote rural areas near Graz, Austria.
- Nélida Aguiar donated hers to Garouta do Calhau, a day centre for persons with dementia.

As in previous years, a free subscription for the 2019 conference in The Hague was also awarded to one lucky participant, drawn at random from the submitted poster evaluations. Romaine Rizzo (Malta) was the winner.

The Alzheimer Europe Foundation is grateful to all 187 conference delegates who voted and all poster presenters for their excellent contributions at the conference.

SPOTLIGHT ON 28AEC

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The Alzheimer Europe Foundation is grateful to all 187 conference delegates who voted and all poster presenters for their excellent contributions at the conference.
Facts and figures

- 96% of delegates would recommend future Alzheimer Europe Conferences to their colleagues.
- 87% of delegates rated the opening ceremony, keynote lecture, plenaries and closing ceremony of the conference to be good/very good.

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- Academics/Researchers: 227
- Alzheimer association staff and volunteers: 209
- Health or social care professionals: 194
- Students: 47
- Industry representatives: 35
- People with dementia: 34
- Carers: 31
- Civil servants: 22
- Policy makers: 15

**Total: 814**
Our members are helping people with dementia and their carers in 37 countries.
29th Alzheimer Europe Conference
Making valuable connections
The Hague, Netherlands
23–25 October 2019

www.alzheimer-europe.org/conferences  #29AEC