Spotlight on 27th AE Conference in Berlin

Heinz K. Becker hosts Alzheimer Europe’s lunch debate in European Parliament

Chris Roberts gives speech at 4th European Parliament of Persons with Disabilities

Adalberto Campos Fernandes Minister of Health announces the first dementia strategy for Portugal
Contents

3 Welcome
by Iva Holmerová Chairperson of Alzheimer Europe

Alzheimer Europe

4 Alzheimer Europe’s European Parliament lunch debate focuses on improving the diagnosis of Alzheimer’s disease thanks to European research collaboration
7 AE organises its third successful Alzheimer’s Association Academy
9 Five-country survey of carers highlights continuing delays in dementia diagnosis across countries
11 Involving people with dementia in European research projects
12 The value of being involved in research
15 Ensuring the voices of people with dementia are heard in research
17 AE publishes Yearbook on care standards for residential care facilities in Europe and a report on dementia as a disability?

Policy Watch

22 Portugal announces first dementia strategy
23 AE members from Portugal, Spain and Malta participate in Alzheimer’s Summit
24 World Health Organisation (WHO) launches the Global Dementia Observatory
28 Council of Europe celebrates 20th Anniversary of the Oviedo Convention: relevance and challenges
32 Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) participates in 4th European Parliament of Persons with Disabilities
35 EU4HEALTH Campaign calls for continued future health collaboration in Europe
38 European news in brief

Dementia in Society

40 Alzheimer Europe welcomes new members from Montenegro
42 Young researchers rise to the dementia challenge in European research

46 Dementia Action Alliance (DAA) campaign gives seldom heard groups a voice
48 A look behind the headlines: ‘Vampire’ therapy

Spotlight on 27AEC

50 Alzheimer Europe Conference opens under the theme “Care today, cure tomorrow”
52 Snapshots from Berlin #27AEC
53 European Working Group of People with Dementia contributes to success of AE conference
55 “Care today, cure tomorrow”
57 Participants at AE Conference “Care today, cure tomorrow” call for increased dementia research funding and collaboration
60 Congratulations to the winners of the poster awards
62 Facts and figures
I am pleased to welcome you to the 26th edition of our Dementia in Europe magazine. I am also pleased to announce that we will be publishing three editions of the magazine this year.

The first section highlights some of Alzheimer Europe’s recent activities to make dementia a European priority, including a lunch debate in the European Parliament focusing on improving the diagnosis of Alzheimer’s disease thanks to European research collaboration. I would like to personally thank our hosts, MEPs Heinz K. Becker (Austria) and Olga Sehnalová (Czech Republic), plus MEPs Nessa Childers (Ireland), Marian Harkin (Ireland), Peter Kouroumpashev (Bulgaria), Lambert van Nistelrooij (Netherlands) and Keith Taylor (UK) for their active participation.

Alzheimer Europe continues to support the rights and dignity of people living with dementia with new publications: the Yearbook on standards for residential care facilities in Europe and our report on dementia as a disability and the implications for ethics, policy and practice. Empowering people with dementia to take part in research, if they so desire, is another important aspect of our work and we are pleased to present our position paper on involving people with dementia in research through patient and public involvement (PPI).

We are also particularly proud of the great work of our European Working group of People with Dementia whose members attended the 4th European Parliament of Persons with Disabilities organised by the European Disability Forum. The group’s Vice-Chairperson Chris Roberts gave a speech highlighting the specific needs of people with dementia.

In the Policy Watch section, we provide updates on interesting policy developments at a global level with the recent launch of the Global Dementia Observatory by WHO, at European level with a focus on the #EU4Health campaign and at national level we take a closer look at the newly announced national dementia strategy for Portugal thanks to an interview with the Portuguese Health Minister.

We are also pleased to launch the new “Europe in Brief” section highlighting key EU news such as the newly signed European Pillar of Social Rights, the relocation of the European Medicines Agency, the mid-term evaluation of the Health Programme and the State of Health in the EU report.

Finally in this section we take a look at the 20th anniversary of the Council of Europe’s Oviedo Convention on Human Rights and Biomedicine.

In the Dementia in society section, we are pleased to introduce the new Alzheimer Europe member organisation from Montenegro. We focus on the work young researchers are doing in dementia and take a look at the real story behind recent media headlines on the “vampire therapy” as a potential way to treat Alzheimer’s disease.

Our “special section” takes a looks back at the success of our 27th Alzheimer Europe Conference “Care today, cure tomorrow” #27AEC held in Berlin. We provide an overview of the key presentations at the opening ceremony and the plenary sessions and focus on the contributions of people with dementia at the conference. This section also showcases the best of the poster presentations as voted by the delegates and provides some great snapshots of the conference.

Happy reading!

Iva Holmerová
Alzheimer Europe’s European Parliament lunch debate focuses on improving the diagnosis of Alzheimer’s disease thanks to European research collaboration

MEPs Heinz K. Becker and Olga Sehnalová hosted a lunch debate showing progress in the development of new tools including the discovery of novel biomarkers for the diagnosis of Alzheimer’s disease at its earliest stages.

“We need more political will at European level to help solve the dementia problem and address the needs of the growing elderly population.”

Heinz K. Becker MEP

“Thanks to biomarkers there has been a paradigm shift in diagnosing Alzheimer’s disease and Alzheimer’s dementia.”

Prof. Philip Scheltens

On 5 December Alzheimer Europe (AE) held a successful lunch debate in the European Parliament co-chaired by MEPs Heinz K. Becker (Austria) and Olga Sehnalová (Czech Republic) which focused on improving the diagnosis of Alzheimer’s disease thanks to European research collaboration. The lunch debate gathered over 95 people including MEPs Nessa Childers (Ireland) Marian Harkin (Ireland) Lambert van Nistelrooij (Netherlands), Peter Kouroumbashev (Bulgaria) and Keith Taylor (UK). The audience included representatives from 24 Alzheimer Europe member associations, several pharmaceutical companies plus all members of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) and their supporters.

Heinz K. Becker MEP, opened the lunch debate and welcomed all participants. Mr Becker stressed the need for more political will at European level to help
solve the dementia problem and address the needs of the growing elderly population. By 2060 28% of the population will be aged over 65 and 12% aged over 80. The number people currently living with dementia is 8.7 million in the European Union and this number is expected to at least double by 2040.

In light of these figures Mr Becker called for better coordination at European level and the need for a high level European coordinator for dementia.

This lunch debate looked at the advances and improvements through European research in diagnosing Alzheimer’s disease (AD). However despite these advances, it is estimated by Alzheimer’s Disease International (ADI) that only a quarter of people with dementia worldwide and half of people in high-income countries have received a formal diagnosis.

A paradigm shift in diagnosing Alzheimer’s disease
The first speaker, Prof. Philip Scheltens, (VU University Amsterdam, Netherlands) said that thanks to biomarkers there has been a paradigm shift in diagnosing Alzheimer’s disease and Alzheimer’s dementia. Prof. Scheltens gave a very interesting historic overview of the diagnosis of AD. For a long time, a diagnosis of Alzheimer’s disease could only be confirmed postmortem after a brain autopsy. One of the undoubted key advances in AD research is the emergence of biological measures (biomarkers) and imaging techniques which allow a definitive diagnosis of Alzheimer’s disease in living persons. Biomarkers can be assessed by neuroimaging i.e. MRI and PET scans or cerebral spinal fluid (CSF) analysis which are also increasingly being used to diagnose Alzheimer’s disease in research studies and specialist clinical settings.

Prof. Philip Scheltens

Prof. Scheltens highlighted the fantastic progress in diagnosis, illustrating that being able to detect brain changes early, now gives a better window of opportunity to help identify new treatments to prevent Alzheimer’s dementia. He said it is easier now through the discovery of amyloid to give a preclinical diagnosis of AD even if there are no symptoms. This in effect means that AD can be diagnosed before the onset of dementia.

2nd European Joint Action on Dementia – Act On Dementia
The second speaker Prof. Pierre Krolak-Salmon (University Hospital of Lyon, France) presented the 2nd European Joint Action on Dementia – Act On Dementia. Prof. Krolak-Salmon highlighted the fact that diagnosis is often too late and post diagnosis support is insufficient as well as inappropriate in many European countries. To address these challenges he introduced a diagnostic framework centred on primary care detection which could promote and enhance a timely diagnosis of Alzheimer’s disease and other neurocognitive disorders thanks to a better collaboration between general practitioners and specialists.

Using big data
In order to redeem today’s great promises of big data and artificial intelligence to change and support clinical practise the third speaker Dr Jyrki Lötjönen, (Combinostics, Helsinki, Finland) introduced the PredictND project’s clinical decision support tool. Currently the time from symptoms to diagnosis can take an average of 20 months in Europe and less than 50% of people get the diagnosis. This new tool compares all patient data (neuropsychology, imaging biomarkers quantified by the tool and cerebrospinal fluid biomarkers) to data from a high number of previously diagnosed subjects to support clinicians in...
their decision making for an accurate diagnosis. In the PredictND prospective study, the clinical decision support tool was evaluated with 800 patients from four European memory clinics. Dr Lötjönen emphasised that artificial intelligence can support clinicians in decision making and the results show that the confidence of clinicians increased on their decisions, enabling earlier diagnosis. In his conclusion Dr Lötjönen said that having more efficient diagnostics is essential in solving the huge challenge of dementias.

The Innovative Medicines Initiative (IMI) supporting unmet needs

The final speaker Dr Elisabetta Vaudano from the Innovative Medicines Initiative (IMI) talked about the IMI portfolio of AD projects supporting research in the diagnosis of Alzheimer’s disease, and how IMI is supporting disease areas with high unmet needs. As well as IMI, the European Union also supports a number of different research efforts on the diagnosis of Alzheimer’s disease and other neurodegenerative disorders through various programmes including the EU health programme, Horizon 2020 and the Joint Programme for Neurodegenerative Diseases Research (JPND).

MOPEAD and AMYPAD projects

The two IMI projects that focus on diagnosis are AMYPAD (Amyloid imaging to prevent Alzheimer’s disease) which looks at the diagnostic value of amyloid imaging and MOPEAD (Models of patient engagement for Alzheimer’s disease) which compares different approaches to engage potential Alzheimer’s disease patients.

AMYPAD’s aim is to explore the impact of amyloid PET imaging on diagnostic thinking in the work-up of patients with SCD-plus MCI, and dementia, to improve the understanding, diagnosis and management of Alzheimer’s disease through the utilisation of β-amyloid PET imaging. The AMYPAD initiative further aims to improve the diagnostic work-up of people suspected to have Alzheimer’s disease and their management to understand the natural history of the disease in a pre-symptomatic stage and select people for treatment trials aiming at preventing Alzheimer’s disease.

More European collaboration

Dr Vaudano stressed the need for collaboration at European but also at global level to address the dementia challenge amongst patients, scientists, industry and healthcare professionals. Dr Vaudano said that despite the fact we still do not have a cure it remains critical to stress the importance of diagnosis; improve access to medical and support services; to provide an opportunity to make legal, financial and care plans while affected individual is still capable; reduce health care costs by delaying placement in a nursing home and current treatments may only work if started early.

This lunch debate showed there has been huge progress in the development of new tools including the discovery of novel biomarkers for the diagnosis of AD at its earliest stages. It is possible that ultimately it will lead to new and better treatments and better disease management. However more and better collaboration is necessary to impact decision making where it matters most for patients. In her concluding remarks, Olga Sehnalová said that it was important to bring the issue of Alzheimer’s disease to the European Parliament and that the new trend in diagnosis gives us hope for a future cure. She then handed over to Iva Holmerová, Chairperson of Alzheimer Europe who thanked everyone for coming including the sponsors of the event, Eisai, GE Healthcare, GSK, Lilly, MSD, Pfizer and Roche.
AE organises its third successful Alzheimer’s Association Academy

The two-day Academy was a highly interactive event, with lots of time for questions after presentations and plenty of lively and thought-provoking discussion. Given the success of its Academies, AE plans to organise a fourth in December 2018

On 5 and 6 December 2017, Alzheimer Europe (AE) hosted its third annual Alzheimer’s Association Academy. Participants included 24 representatives from AE member organisations, 4 company representatives and 4 AE staff members. There were 14 expert speakers including a representative of the European Working Group of People with Dementia (EWGPWD) and topics were defined based on a survey of participants at the 2016 Academy and AE members.

**The role of Biomarkers in diagnosis**
The first day began with a session on “The role of biomarkers in the diagnosis of Alzheimer’s disease/dementia” and was moderated by Charles Scerri, from the Malta Dementia Society. This session included presentations by Marialma Boccari from the University of Geneva, Switzerland, Pierre Krolak-Salmon, from the Institut du Vieillissement, Lyon, France and Richard Milne from the University of Cambridge, UK. This interactive session built on the presentations provided at the European Parliament lunch debate earlier in the day on “Improving the diagnosis of Alzheimer’s disease thanks to European research collaboration (for more details see page 4). During their presentations the speakers addressed the key questions: How have biomarkers impacted the diagnosis of Alzheimer’s disease/dementia? How do national organisations communicate about the changing definition of Alzheimer’s disease/dementia? What are the implications for clinical practice of new research criteria? How can Alzheimer’s associations support communication activities on the meaning of biomarkers and risks of developing dementia?

**Research collaboration**
The second session of the day was on “EU research collaboration on timely diagnosis – Opportunities for collaboration with Alzheimer’s associations” and was moderated by Iva Holmerová, Chairperson, Alzheimer Europe. This session included presentations by Laura Campo from Lilly, who presented the key aims of the MOPEAD (Models of patient engagement in Alzheimer’s disease) project and...
Isadora Alves (VUMC, Netherlands) who presented the key aims of the AMYPAD (Amyloid Imaging to Prevent Alzheimer’s disease) project. Both speakers illustrated how the projects can support earlier diagnosis of Alzheimer’s disease and dementia.

Day two of the Academy began with a session on “Patient and public involvement in dementia research” which was moderated by Jean Georges, Executive Director, Alzheimer Europe. This session included presentations by Helen Rochford-Brennan Chairperson of the EWGPWD and Dianne Gove, Director for Project, Alzheimer Europe who presented “The experience of Alzheimer Europe in involving the European Working Group of People with Dementia in Research. Wendy Werkman from Alzheimer Nederland, Netherlands presented “The experience of Alzheimer Nederland in involving carers in research” and Stina Saunders from the University of Edinburgh, UK presented “The participant panel in EPAD (European Prevention of Alzheimer’s dementia) as a model of involving research participants in research”. All speakers helped give delegates a deeper understanding of how Alzheimer associations can involve people with dementia and carers in research projects and how research can benefit from this input.

Real world evidence in dementia research
The second morning session, was on Real World Evidence in dementia research and was moderated by Chris Bintener, Project Officer, Alzheimer Europe. The session focused on the ROADMAP project. Catherine Reed from Lilly, UK presented “The aims of the ROADMAP (Real world outcomes across the Alzheimer’s disease spectrum for better care: multi-modal data access platform) project”. Marieke Dekker from the Medicines Evaluations Board, Netherlands presented “The use of real world data and evidence in regulatory and health technology assessments” and Andrew Turner from the University of Oxford, UK presented “Ethical issues raised by big data and real world evidence projects”. This session introduced the aims and objectives of the ROADMAP project and showed how real world data can support the development process of new medicines and looked at the question of how do big data projects address ethical issues.

European Union funding opportunities for Alzheimer’s Associations
The final session was moderated by Vanessa Challinor, Policy Officer, Alzheimer Europe. It was dedicated to EU programmes and their relevance for Alzheimer associations. The first two speakers were from the European Commission, Andor Urmos presented “Funding opportunities for national activities from the European Regional Development Fund and the European Social Fund” and Isabel de la Mata presented “The European Solidarity Corps and opportunities for national Alzheimer’s associations” . The final speaker of the Academy Christine Marking from Eurocarers presented “The European Social Pillar and its implications and relevance for carers of people with dementia”. This session provided an opportunity for national Alzheimer Associations to learn more about a number of key European programmes and initiatives and how these can support national organisations and carers.
Five-country survey of carers highlights continuing delays in dementia diagnosis across countries

On 3 October at the 27th Alzheimer Europe Conference in Berlin, Prof. Bob Woods presented the top line results of a five-country survey on the experience of 1,409 carers of a diagnosis of dementia.

The five-country carers’ survey was conducted in the Czech Republic, Finland, Italy, the Netherlands and in the United Kingdom (Scotland) and was made possible thanks to an educational grant from Roche to Alzheimer Europe. The survey was developed by Prof. Bob Woods from the University of Bangor (Wales, United Kingdom) in collaboration with representatives from Alzheimer Europe, Alzheimer Nederland, Alzheimer Scotland, the Czech Alzheimer’s Society, Federazione Alzheimer Italia and the Finnish Alzheimer’s Society.

Over 1,400 carers provided invaluable insights into their experiences of the diagnosis of dementia.

Prof. Bob Woods

The survey was available in five European languages in both on-line and paper versions. The link to the on-line survey was distributed through the participating national Alzheimer’s association and the paper version made available on request or mailed out according to local circumstances. The paper version was not used in the Netherlands. The plan was to achieve a target of 200 completed carer surveys in each of the 5 participating countries. In the end, this number was exceed in each country.

<table>
<thead>
<tr>
<th>Country</th>
<th>On-line surveys</th>
<th>Paper surveys</th>
<th>TOTAL</th>
</tr>
</thead>
<tbody>
<tr>
<td>Scotland</td>
<td>211</td>
<td>16</td>
<td>227</td>
</tr>
<tr>
<td>Italy</td>
<td>193</td>
<td>146</td>
<td>339</td>
</tr>
<tr>
<td>Netherlands</td>
<td>268</td>
<td>7</td>
<td>268</td>
</tr>
<tr>
<td>Finland</td>
<td>356</td>
<td>7</td>
<td>363</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>150</td>
<td>62</td>
<td>212</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>1178</strong></td>
<td><strong>231</strong></td>
<td><strong>1409</strong></td>
</tr>
</tbody>
</table>

Prof. Bob Woods, Berlin 2017

![Prof. Bob Woods, Berlin 2017](image-url)
Main findings of the survey

- The majority of participating carers were women (82.8%) in all participating countries (ranging from 75.8% in the Netherlands to 88.4% in Scotland).
- Differences existed with regard to the relationship of the carer to the person with dementia with a majority of participating carers in the Netherlands being spouses or partners (53.7%) whereas the largest group in all other participating countries were the children of the person with dementia (ranging from 45.8% of carers in Scotland to 64.8% in Italy).
- On average, 47% of carers felt that the diagnosis would have been better earlier (ranging from 36.5% in the Netherlands to 52.1% in Italy).
- Amongst the key identified barriers to earlier diagnosis, carers reported the first professional seen not considering that anything was wrong (33%) or believing it was not worth pursuing a diagnosis (6.6%) and the refusal of the person with dementia to seek help (37.9%).
- Carers reported that in a number of cases (19.2% in the Netherlands to 31.8% in the Czech Republic and 31.9% in Italy), another condition was diagnosed before the diagnosis of dementia was made.
- The role of healthcare professionals involved in the diagnosis of dementia differs between European countries with the percentage of carers reporting that they first sought help from GPs/primary care ranging from 31.9% in Italy to 83.9% in Scotland.
- Carers also reported differences as to the assessments which are carried out as part of the diagnosis with memory tests being reported by 78.7% of carers in the Czech Republic to 92.8% of carers in Finland, interviews with the person with dementia from 62.3% in the Czech Republic to 86.7% in Italy, blood tests from 31.8% in Italy to 64.2% in Finland, brain scans from 56.1% in the Czech Republic to 84.3% in Finland and lumbar punctures from 1.7% in Scotland to 18.3% in the Netherlands.
- Significant differences exist across European countries as to the percentage of people with dementia being informed about their diagnosis with 59.3% of Italian carers reporting that the person had not been informed about their diagnosis and this percentage falling to 23.2% in the Czech Republic, 8.2% in the Netherlands, 4.4% in Scotland and 1.1% in Finland.

When presenting the findings, Prof. Bob Woods highlighted: “Over 1,400 carers provided invaluable insights into their experiences of the diagnosis of dementia. We were particularly interested to see whether there were differences between people who had been diagnosed more recently (after 2013) compared to those who had been diagnosed earlier. Several countries have dementia strategies and there is growing public and professional awareness. It was encouraging to see that medical professionals were less likely to be a barrier to diagnosis in all countries with the number of professionals considering that nothing was wrong decreasing from 36.8% to 28.7%. We will of course further analyse these results and present them in a scientific paper later this year.”

Welcoming the results, Jean Georges, Executive Director of Alzheimer Europe said: “Thanks to the participating carers, we are better able to understand the existing barriers which still exist across Europe which delay people with dementia and their carers getting a timely diagnosis.”

The final care survey results will be presented on 26 June 2018 in the European Parliament, Brussels at the Alzheimer Europe Lunch debate, “Dementia care in the European Union.”
Involving people with dementia in European research projects

On 4 and 5 September 2017 the European Working Group of People With Dementia (EWGPWD) provided guidance and first-hand insights to ROADMAP with the aim of creating a consensual list of meaningful outcomes across the course of Alzheimer’s disease.

Alzheimer’s disease and dementia – A European challenge
In the context of an ageing population, Europe is facing an acute healthcare challenge. In no area is this more apparent than in dementia, and in the absence of a cure, challenges in the evaluation of early disease interventions within the current assessment systems have not changed. Consequently, the precision medicine approach to health funding requires new models that encompass all available evidence for the identification of best-suited treatments for different groups.

IMI a public-private partnership aiming to speed up the development of better and safer medicines
“You can’t design a study about a disease if you don’t understand it” and who is a better expert by experience than a person actually living with the disease.

For decades, the involvement of patients in research was solely based on participation in studies and trials as research subjects. In order to overcome this, the Innovative Medicines Initiative (IMI), a joint undertaking between the European Union and the European Federation of Pharmaceutical Industries and Associations, has taken active steps to promote active patient involvement over the past years.

Towards a step-change in understanding Alzheimer’s disease in the real world
Since 2016, Alzheimer Europe (AE) has been part of the ROADMAP consortium, an ambitious IMI-funded project aiming to provide the foundation for an integrated data environment and framework for real-world evidence (RWE) in Alzheimer’s disease.

The focus of research towards understanding the effects of a drug treatment traditionally relies on data collected in the context of clinical trials. Although, findings of a clinical trial are very valuable and this type of approach has several benefits, it also has shortcomings. For example, clinical trials take place in highly controlled settings that may not reflect the real lives of the participants. Moreover, people who are frail or in poor health, have other diseases in addition to dementia or are taking other drugs, are often excluded from participation. In other words, data collected in clinical trials may not always depict the “real world”.

In recent years, there has been a shift to better reflect what happens in real life, and many concepts which include the label “real-world” are currently used: real-world studies, real-world data and real-world outcomes etc. A common aspect is the interest in high-quality information collected outside of clinical trials to support decision-making in healthcare. Examples include: information documented in daily care when people are consulting their general practitioners or information included in patient registries.

This new approach has the potential to contribute to a fuller understanding of the benefits and risks to patients when taking a treatment. However, it also has challenges (e.g. ethical issues, social implications, deficiencies in a consensus on appropriate outcomes from non-clinical trials).

Understanding priority outcomes
Understanding which outcomes are of importance along the patient pathway from the first pre-symptomatic phases of dementia through to severe cognitive and functional decline and, eventually, death, is crucial to inform the design and execution of intervention and observational studies.

ROADMAP’s work stream “Outcome Definition” aims to obtain consensus on a set of real-world Alzheimer’s disease (AD) focussed outcomes across the spectrum of the patient journey from pre-clinical to severe stages. The collaboratively generated outcomes will be those relevant to patients, carers, scientists, clinicians, regulators, Health Technology Assessment bodies, payers and policy makers.
Involvement of people with dementia

Alzheimer Europe (AE) is keen to promote the involvement of people with dementia in research and in 2012 set up the European Working Group of People with Dementia (EWGPWD). The group provides feedback and advice to AE in relation to its own work and its involvement in various EU projects and is currently comprised of 10 people with different kinds of dementia.

On 4 and 5 September (2017), AE organised and jointly facilitated a consultation with the EWGPWD and ROADMAP project colleagues from the University of Edinburgh to consult on their project activities within the work stream “Outcome Definition”.

For the sake of acquiring insights on both people with dementia and carers own lived experiences, the attendees split into two groups (one consisting of the members of the EWGPWD and the other of their carers/supporters) with a couple of joint feedback sessions.

The sessions included discussions on disease progression, addressing the usefulness of terms describing stages, as well as what changes indicate progression. Other discussions focused on treatment and research surrounding hypothetical drugs that could either delay the onset of dementia or slow down its progression. This was concluded with a summing up of what a meaningful delay in disease progression might entail and how meaningful real-world evidence could potentially be captured. In addition, both groups provided feedback on a survey, designed to determine which outcomes are most important and most helpful in understanding AD progression.

Mia Nelson, ROADMAP project

“Specifically working with the EWGPWD itself has been amazing, there is such a good collaboration between the group members themselves and us. They are an amazingly dynamic group, the like of which I haven’t worked with before. They have made such valuable contributions and came with such a willingness to share and work with us. It’s been an absolute pleasure and I can’t imagine what it would be like to try and do this without their input and guidance.”

The value of being involved in research

In this section, Chris Roberts – Vice-Chair of the EWGPWD and his wife Jayne Goodrick provide us with some first-hand insights about their involvement in the ROADMAP project consultation. Chris was diagnosed with mixed dementia in early 2012 but has not let this diagnosis get in the way of leading a full life. He spends most of his time promoting and providing education to others about dementia.

AE: How do you feel about the consultation in Luxembourg?
Chris: I always find working with the EWGPWD very enjoyable, everyone’s supportive of each other and it’s a very relaxing atmosphere. You haven’t got a lot of hope left when you receive a diagnosis.

“Working in an environment like this gives confidence back, gives value and a sense of purpose. The main thing is that the research you’re doing in ROADMAP actually gives us hope as well. This hope is not only for us; it also gives us hope for our children, while we’re getting that value and actually using our own expertise.”

While the professionals work very hard to gain their expertise, we live with the illness. In this context there are things that the professionals maybe can’t find
out on their own. So it’s great to work together and while we’re doing that work I learned so much that actually helps me understand my own illness as well.

Jayne: I thought it was going to be a little bit flat and a little bit dry. It was anything but that. It was an extremely rich and powerful experience. The consultation gave me a great deal of excitement and anticipation about looking at the real-world and starting to collect real-world data. I see that this work can actually have an impact on people’s lives. Perhaps the main thing I took away was that this work triggers thought mechanisms in people, contemplating what they need to put into place for later on, when things would be more advanced than they are now. While some of the topics raised were not easy issues to discuss, these were the conversations that we at home, living with dementia, need to have. The on-the-ground aspects of the consultation, the actual surveys, will make people think and start having those conversations, as it allows the subjects to be brought up. It is good that everybody’s views, wants and needs were able to be voiced. I think it’s helpful for later on, when Chris, or the person with dementia, is less able to voice an opinion or desire, as those conversations have already happened.

Chris: The actual research that you’re doing at the moment with your project is quite radical in thought, because it’s different from the usual data that’s collected. I am very aware that the usual research that carries on or has been happening and the usual questions that are asked and answered are obviously not working that well, because otherwise we would have come up with something better by now with regard to treatments and management. I am quite thrilled and excited about the thought and I think collecting data that’s all around us and using data that people don’t usually collect for research is quite exciting.

Jayne: I like the aspect that the real-world data that will be collected is going to inform the researchers’ outcomes, rather than only looking in a particular area and trying to see if the data fits their hypotheses. In this case it might be possible that this will guide them down avenues that may not have been considered before.

AE: What would be the most important points you would like to tell the scientists in ROADMAP?

Chris: Regarding the most important things that came out of the consultation, I think one is to involve the experts by experience at a much earlier date. Maybe this could even help to save some time and money. I’d also like to say that assumptions shouldn’t be made against anyone affected by dementia, because that’s not all they are. People affected by dementia might have been professors, researchers, scientists themselves. We mustn’t forget their backgrounds and the experiences they might have had in their jobs.

Jayne: The same thing applies to the carers, they too were once scientists, researchers, physicists etc. and

“Working in an environment like this gives confidence back, gives value and a sense of purpose.”

Chris Roberts

“I think it is about the importance of all of us working together and that we all have our place to fulfil.”

Chris Roberts
then they become “just the carer”. They too have a wealth of knowledge and experience. The message I would like to send back though, is that while these surveys – because that was what we were concentrating on in our work programme – may seem to be a very blunt tool, I strongly recommend not to make the assumption that they will be flat. The surveys will bring up a lot of issues on both sides of the coin for people with dementia and carers and can raise all sorts of issues and emotions that might otherwise not have been addressed. Providing support for those mechanisms can just be something as simple as a helpline. Don’t forget that even a “blunt instrument” can have very lasting effects on the people that are involved.

Chris: I’d like to thank everyone involved in the ROADMAP project for including those affected by dementia, the people diagnosed and their carers and supporters. It’s definitely the right way to go. I’d also like to thank the researchers for their understanding and patience during the consultation, because it’s not always easy to work with someone with dementia, especially a whole team. I thought it went very, very well and I’d like to further give my appreciation to all the researchers out there that are doing these things for our benefit.

Jayne: I echo what Chris has said. Additionally, I’d like to express my admiration for the sensitivity the researchers showed during the consultation, whilst maintaining a very professional attitude. They have maintained a professional distance without losing the human touch.

AE: How do you feel about being involved as an expert by experience in ROADMAP?

Chris: Being involved ourselves reminds us of the great work that is going on that a lot of the general public never hear or know about because most of the things the general public does hear are obviously the failures. It’s a problem that the media is so focussed on bad news. It’s great to be involved and gain more of an insight into what’s going on and then we can take that back into other groups and peer support groups and actually give them hope, so it has a massive knock-on effect being involved in your great work.

Amanda Ly, ROADMAP project

“I thoroughly enjoyed the lively and thought-provoking discussions that we had during our consultation with the EWGPWD. Gaining invaluable insights from their firsthand experience of living with dementia enables us to better understand topics of our research, which include: priority dementia-focussed outcomes; how to define meaningful delay in disease progression, and how these could potentially be captured as real-world evidence. Continuing to involve people with dementia and their carers in scientific research will provide important contributions towards developing more effective, patient-centred treatment and care. I look forward to further collaborations with the EWGPWD in the near future.”

This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 116020 (“ROADMAP”). This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.
Ensuring the voices of people with dementia are heard in research

Public and Patient Involvement (PPI) promotes meaningful and active involvement of people with dementia in the context of research and policy development

In the last few decades, there has been an increasing international emphasis on involving patients, informal caregivers (including people with dementia and their supporters) and the general public in various aspects of healthcare, including health-related research and policy making. It was long assumed by many researchers that the accounts of people with dementia were not reliable and consequently, their voices were not heard. However, experience has shown that many people with dementia can be meaningfully involved in research and contribute towards policy making provided that appropriate support is provided when needed. Such involvement represents a positive step towards the inclusion of people with dementia in matters which are relevant to their lives and recognises the valuable contribution they can make to society.

Public and Patient Involvement (PPI) is an approach which seeks to promote meaningful and active involvement of people with dementia and represents a true partnership between people with dementia, researchers and, when appropriate, policy makers and other members of society. It is about carrying out research and developing policies with or by people with dementia rather than on or for them as mere participants. This is very much in keeping with the slogan of the disability movement “nothing about us without us” and reflects the right of people who are likely to be affected by the results of research to have a say in what and how publicly funded research is undertaken. In some countries, PPI has become a central element of government policy and an ethical requirement for health research.

In 2016, Alzheimer Europe started to explore the concept of PPI with the INTERDEM (Early detection and timely INTERvention in DEMentia) research group and held a consultation with Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) with the overall aim of developing a joint position paper on involving people with dementia in research through PPI. Together, we reflected on the challenges and potential risks and benefits associated with the meaningful involvement of people with dementia in research conducted by Alzheimer Europe or in collaboration with external researchers (please see the executive summary from this paper).

Alzheimer Europe has been involving people with dementia in all its work since 2000. Initially, we relied on individuals who came forward and volunteered to contribute towards our projects. In this respect, we are immensely grateful to the late Peter Ashley and also to James McKillop (MBE) who were influential in providing a voice for people with dementia at a time when far fewer people were willing to do so, and showing us through their contributions just how important it is to do so. In 2012, the EWGPWD was set up to advise Alzheimer Europe on all of its activities and projects. Since then, the EWGPWD has been involved in several research projects in which Alzheimer Europe is a partner and has provided input through PPI work, some of which has been reported in peer-reviewed journals.

The position paper has highlighted several important issues which we feel must be addressed whenever people with dementia are asked to
Executive summary from “Alzheimer Europe’s position on involving people with dementia in research through PPI (patient and public involvement)” by Gove et al. (2017) 1

1. Alzheimer Europe is keen to promote the involvement of people with dementia in research, not only as participants but also in the context of Patient and Public Involvement (PPI) by generating ideas for research, advising researchers, being involved in consultations and being directly involved in research activities. This position paper is in keeping with this objective.

2. Involvement enables people with dementia to assist in identifying research priorities and the nature of the research to be undertaken, influence the direction and conduct of research, have their voices heard and, in so doing, contribute towards the quality, relevance and ethical conduct of research.

3. PPI should be planned, incorporated into the study design, budgeted for, documented and monitored.

4. Funders and ethics committees should expect the full engagement of people with dementia and raise questions if this is not the case. PPI should always be meaningful, rigorous and enhance the research process. It should never amount to tokenism or “box ticking” (i.e. either not using their input or involving them in an activity that is not needed simply to be able to claim that they were involved).

5. Researchers should take all necessary measures to ensure the safety and wellbeing of people with dementia who are contributing towards PPI. However, they should avoid being over protective/paternalistic and be willing to challenge stereotypes about dementia which may hamper this kind of involvement.

6. Contributing towards PPI is not the same as being a research participant. Nevertheless, some PPI activities may carry a risk of harm or distress either to the people engaged in PPI or to others. Researchers should therefore check whether they need ethical approval (e.g. for consultation activities or when there may be contact with research participants who have dementia) and whether there are any relevant legal regulations that might be applicable in the country in which the research is being conducted.

7. Irrespective of whether ethical approval is required for PPI, researchers should ensure that people with dementia understand what the research is about, the role they are being asked to play, the skills or experience needed, any support or training that might be offered and that they are free to withdraw at any time.

8. All costs incurred as a result of PPI (e.g. travel, accommodation and meals) should be covered and, whenever possible, provided upfront.

9. The contribution made by people with dementia should be fairly, appropriately and openly acknowledged in a way that is acceptable to the individuals concerned.

---

AE publishes Yearbook on care standards for residential care facilities in Europe and a report on dementia as a disability?

Alzheimer Europe continues to support the rights and dignity of people living with dementia with new publications

Standards for residential care facilities in Europe

The 2017 Yearbook is a comparative report focusing on the topic of residential care facilities in Europe and provides an overview of the existing care standards and regulatory requirements that these facilities need to meet. The report addresses key areas that have a great impact on the people living in residential care, namely, the physical environment, the staff providing care, health and social care and human rights, end-of-life care and abuse and restraint.

The information for the 2017 Yearbook was primarily provided by Alzheimer Europe’s members. In some countries other national experts were also contacted (e.g. Belgium, Austria, Cyprus, Bulgaria, Cyprus, Latvia and Lithuania). Members of the European Working Group of People with Dementia (EWGPWD) were invited to share their experiences with and views on each of the topics addressed in the report by providing a short personal accounts.

The quality of care provided in residential care facilities in Europe is a complex and challenging topic. There are important differences in the way long-term care is organised and provided across Europe due to cultural, economic and political factors. The organisation and provision of residential care in Europe is heterogeneous, with relevant differences in the type of facilities providing care, the funding mechanisms and the regulatory systems for the implementation and overseeing of the quality of the care and support provided in these care settings. Previous research in this area, has shown that the environment, workforce and the care provided are key elements of the quality of care provided and are often part of the minimum requirements regulated in Europe. In addition to those, recent evidence suggests that, residents’ rights (particularly choice and involvement), end-of-life care and abuse (particularly the unlawful or inappropriate use of restraint) may also be key aspects which are highly relevant to the people receiving the care provided in these care settings.

In Europe, the majority of people with dementia live in the community. However, some, may need to move into residential care due to dementia or other conditions. Also, some people living in residential

Table 1: Participating countries

<table>
<thead>
<tr>
<th>EU Member States</th>
<th>Non-EU Countries</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>Norway</td>
</tr>
<tr>
<td>Belgium (Flanders)</td>
<td>Switzerland</td>
</tr>
<tr>
<td>Belgium (Wallonia)</td>
<td>Turkey</td>
</tr>
<tr>
<td>Bulgaria</td>
<td></td>
</tr>
<tr>
<td>Croatia</td>
<td></td>
</tr>
<tr>
<td>Cyprus</td>
<td></td>
</tr>
<tr>
<td>Czech Republic</td>
<td></td>
</tr>
<tr>
<td>Finland</td>
<td></td>
</tr>
<tr>
<td>France</td>
<td></td>
</tr>
<tr>
<td>Germany</td>
<td></td>
</tr>
<tr>
<td>Greece</td>
<td></td>
</tr>
<tr>
<td>Hungary</td>
<td></td>
</tr>
<tr>
<td>Ireland</td>
<td></td>
</tr>
<tr>
<td>Italy</td>
<td></td>
</tr>
<tr>
<td>Latvia</td>
<td></td>
</tr>
<tr>
<td>Lithuania</td>
<td></td>
</tr>
<tr>
<td>Luxembourg</td>
<td></td>
</tr>
<tr>
<td>Malta</td>
<td></td>
</tr>
<tr>
<td>Netherlands</td>
<td></td>
</tr>
<tr>
<td>Poland</td>
<td></td>
</tr>
<tr>
<td>Portugal</td>
<td></td>
</tr>
<tr>
<td>Romania</td>
<td></td>
</tr>
<tr>
<td>Slovenia</td>
<td></td>
</tr>
<tr>
<td>Spain</td>
<td></td>
</tr>
<tr>
<td>Sweden</td>
<td></td>
</tr>
<tr>
<td>UK (England)</td>
<td></td>
</tr>
<tr>
<td>UK (Northern Ireland)</td>
<td></td>
</tr>
<tr>
<td>UK (Wales)</td>
<td></td>
</tr>
<tr>
<td>UK (Scotland)</td>
<td></td>
</tr>
</tbody>
</table>

Ana Diaz

This Dementia in Europe Yearbook received funding under an operating grant from the European Union’s Health Programme (2014-2020).
care facilities may develop dementia at some point of their lives. It is still a challenge to estimate which proportion of people living in residential care facilities have dementia. Also, it should be borne in mind that, whilst an important number of residents may experience cognitive impairment or dementia, several never receive a diagnosis.

The 2017 Yearbook provides information about the regulatory framework for residential care facilities in the participating countries. Although many of the existing standards and requirements for older people in residential care are relevant to people with dementia, only in a few, the specific needs of people with dementia living in these settings are addressed. The report also highlights existing guidelines or standards of care for people with dementia, but in the majority of the cases, these are not specific for residential care. This is an important gap as people with dementia often have more complex needs than other residents and, as dementia progresses, some may be less able to defend their interests and rights, make decisions or communicate preferences.

In relation to the physical environment, the report provides information on the requirements related to the design and layout of the facility; lighting, heating and ventilation; adaptation and equipment to maximise residents’ independence and bedrooms, communal and outdoor spaces. Important differences between countries are highlighted in the report, also, in some cases the standards and requirements are quite detailed and specific, whilst in others the facility has greater leeway to decide how to meet the standards.

The report provides information on the workforce, in particular on the requirements of the manager of the facility, composition of the team, and required ratios, qualification and training of the staff. For this topic it was particularly difficult to draw conclusions. Required ratios and qualifications can be related to the type of residential care facility, type of care and services provided and residents who are most likely to live in these facilities. Also, ratios need to be considered along with the composition of the team providing care, ratios for other health and social professionals present in the facility and required training and skills. Nevertheless, an important gap identified in this area was related to dementia training. For example, the majority of the countries did not have any provisions for staff training on the topics of abuse, restraint, end-of-life care or management of behaviour that challenges.

The report also addresses the topics of care provided (e.g. admission, assessment of needs and care plans, participation and involvement), end-of-life care (involvement of resident and family, last moments of life and training) and abuse and use of restraint. The lack of standards regarding use of restraint and end-of-life care for people living in residential care settings are some of the most concerning gaps identified in the report, especially as a lot of people with dementia spend their last days of life and die in these settings. The use of restraint also represents significant ethical and legal challenges and is a topic of particular relevance to people with dementia who may be vulnerable and unable to understand and express their wishes. Restraint should seldom if ever be used on people with dementia, and if used monitored and for the shortest period of time.

In summary, the 2017 Yearbook provides an overview of existing requirements and standards for residential care facilities. It highlights some important oversights on how dementia is currently addressed or neglected in frameworks and standards in Europe. However, it also highlights examples of good practices in these areas across Europe. Some of the key issues that still need to be considered at policy level are the formulation of clear and legally binding standards with specific considerations of the needs of residents with dementia, appropriate training for staff, awareness raising and the provision of high-quality accessible information to residents, families and staff about their rights and what they should be able to expect from care. We hope this comparative report will be useful in advancing the understanding of this topic and improving the standards of care and the quality of life of people with dementia in residential care.

The 2017 Dementia in Europe Yearbook received funding under an operating grant from the European Union’s Health Programme (2014–2020).
Dementia as a disability? Implications for ethics, policy and practice

This year, Alzheimer Europe set out to explore the possible implications for ethics, policy and practice of accepting dementia as a disability. Article 1 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD, 2006) states, “Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” This clearly applies to the situation and experience of many people with dementia. The provisions contained in the CRPD reflect a social model of disability which emphasises that disability is not merely a matter of biological impairment (the emphasis of the medical model of disability) but also, and perhaps primarily, a social phenomenon. However, we have to be careful not to attribute all disability related to dementia to external factors and in so doing, to overlook how various impairments are actually experienced by the person concerned.

The World Health Organisation (WHO) claims that a good model of disability is “one that synthesizes what is true in the medical and social models, without making the mistake each makes in reducing the whole, complex notion of disability to one of its aspects” (WHO 2002, p.9). This synthesis, according to the WHO, results in a coherent view of different perspectives of health (biological, individual and social), which has clear parallels to the biopsychosocial model of dementia. The concept of disability is constantly being challenged and refined. The reinterpreted social model of disability, for example, gives greater emphasis to the personal experience of disability, in addition to social and environmental factors. This includes the way a person experiences a particular condition, impairment or disability (e.g. not necessarily as a personal disaster but in terms of personal growth and spiritual, philosophical or psychological benefits). It takes the focus off a socially constructed definition of disability, based on deficiency and departure from the norm, onto one which reflects how disability is experienced by people with disabilities.

It was therefore extremely important for Alzheimer Europe, when working on this topic, to ensure that the experience and perspectives of people with dementia were included, in addition to the essential and valuable input from experts in the fields of disability, dementia, law, anthropology, psychology and policy. We involved the whole of the European Working Group of People with Dementia (EWGPWD) in this work right from the start, first by asking them about their perceptions of disability and dementia (i.e. before starting to explore the topic together) and then through a one-day face-to-face consultation and subsequent involvement in the development of an accessible version of the full report. Two members of the EWGPWD (Helen Rochford-Brennan and Helga Rohra) were also members of the expert ethics group, chaired by Dianne Gove, the other members being June Andrews, Andrea Capstick, Carmel Geoghegan, Jean Georges, Sébastien Libert, Grainne McGettrick, Simo Vehmas and Toby Williamson. We are immensely grateful to these two groups for all their work on this discussion paper.

The meanings associated with disability, how we make sense of disability and how society as a whole respond to people with dementia and disability may all change over time. In keeping with the claim of the disability movement “Nothing about us without us”, we need to ensure that people with dementia contribute towards the ongoing refinement of disability-related terms and challenge them when needed. It was great to hear Chris Roberts, Vice Chair of the EWGPWD, pass on this message to several hundred people at the 4th European Parliament of Persons with Disability in Brussels recently. We also need to ensure that subsequent developments in the field of disability also correspond to the experiences, needs and wishes of people with dementia.

The EWGPWD and the expert ethics working group emphasised the importance that recognising dementia as a disability can have in terms of helping ensure that people with dementia enjoy the same human rights and equality under the law as other members of society. The CRPD is an important piece of international legislation in this respect and a tool that people with dementia, their supporters, Alzheimer associations and other organisations can use to advocate for change. Much of what has been accomplished to date in challenging discrimination against people with disabilities and improving their quality of life is the result of people with disabilities coming together to fight for a common cause and to bring about changes in their lives. The founders of the disability rights movement, primarily people with significant physical disabilities and sensory impairments, promoted the idea that people with disabilities were best placed to...
determine what their needs were and to find the most appropriate solutions. This, combined with a call for the de-medicalisation of disability and de-institutionalisation, involved a quest for social, economic and political recognition and to the gradual expansion to include people with other disabilities. Alzheimer Europe was pleased to be accepted as an Ordinary Member of the European Disability Forum in 2016 and is keen to play a role in the further development of the disability movement through supporting the involvement of people with dementia in relevant debates and activities.

Recognising dementia as a disability is not only a matter of claiming rights, autonomy and independence. It must also address care and support needs, and give more focus to a positive conceptualisation of interdependency (reflecting the idea that throughout our lives we are all dependent in different ways on each other). We need a more nuanced understanding of these concepts, and to reflect on how to recognise and promote capabilities, agency, personhood and social inclusion within a broad framework of disability and in relation to dementia. These issues are addressed in detail in the discussion paper.

Finally, we must bear in mind that people with disabilities do not constitute a single, unified group of people, do not all experience disability in the same way and do not all have the same goals. Neither dementia nor disability is the sum total of a person’s identity. Similarly, not everyone with dementia wants to even identify with disability. Doing so can have an emotional and psychological impact. Some people fear that they will be stigmatised if they identify with disability. Others may feel that disability is less stigmatising than dementia, and that being considered as having a disability is empowering. We still need to know more about what people with dementia think and feel about dementia as a disability.

To conclude, examining dementia as a disability brings a new complexion to the more traditional views of dementia. Alzheimer Europe’s discussion paper calls for a progressive and positive change in society’s response to dementia, based on recognition of potential disability, accompanied by a change in attitudes and the provision of coordinated, appropriately funded and properly monitored policies, services and support (please see the recommendations from the discussion paper on the next page). None of these potential benefits should require a particular person with dementia to identify with disability. We need to be careful to recognise and respect difference and individual choice. It is hoped that this paper will contribute towards improving the lives of people with dementia who experience disability. We hope that it will also provoke thought on how to create a more inclusive society in which people with disabilities and dementia are not considered as ‘other’ or ‘them’, but simply as ‘us’ with the same rights, opportunities and support, if needed, as everyone else to enjoy life.

Recommendations (approved by the Board of Alzheimer Europe)

Governments and policy makers
- Use the ongoing evaluation of progress with the implementation of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) as an opportunity to highlight whether national provisions apply equally to people with dementia. If this is not currently the case, take necessary measures to rectify this in order to ensure that dementia is considered in relation to all policies linked to the application of the CRPD.
- Involve people with dementia in the CRPD ongoing evaluation process (e.g. by asking them to provide testimonies and commentaries).
- Audit, and revise where necessary, official information and guidance regarding people with dementia.
disabilities aimed at government departments and agencies, employers, businesses, organisations, and members of the public. This includes appropriate references to dementia as a condition which can give rise to impairments that can constitute a disability, and how disability legalisation and rights would apply for people with dementia.

- Ensure that people with dementia have equal access to provisions and services for people with disabilities (e.g. disabled parking badges, free travel on public transport, appropriate support in the workplace etc.).
- Audit, and revise where necessary, training provided to all public sector staff with responsibilities for applying and upholding disability legalisation and rights, to ensure they are aware of and understand their duties and responsibilities to people with dementia when the impairments it causes constitute a disability.
- Audit, and adapt where necessary, public spaces and buildings to ensure they are accessible to people with dementia and other cognitive disabilities.
- Use the PANEL principles to inform policy and service development in a way that incorporates a rights-based approach and ensure that people with dementia are included in this. This is particularly important when countries are developing national dementia strategies.
- Meaningfully involve people with dementia and carers/supporters in the service developments and audits described above in accordance with PANEL principles.

Alzheimer Associations

- Support people with dementia and carers to be on the boards and decision making structures of Alzheimer Associations.
- Support the active participation of people with dementia in relation to their own self-advocacy in policy development/research and political engagement.
- Enshrine the principle of elevating the voice of the person with dementia and placing the person with dementia at the centre in the organisation’s overall principles and ethos, whilst also recognising the vital role played by carers and supporters.
- Audit and revise where necessary, services and information provided to ensure they meet disability and human rights legislation as it applies to people with dementia.
- Use the PANEL principles to inform organisational and service development in a way that incorporates a rights-based approach and ensure that people with dementia are included in this.
- Actively pursue opportunities for taking test cases to court regarding possible disability discrimination against people with dementia.
- Meaningfully involve people with dementia and carers in the service developments and audits described above in accordance with PANEL principles.

Organisations of, or for persons with disabilities

- Audit, and revise where necessary, services and information provided to ensure they comply with disability legalisation and rights as they apply to people with dementia to ensure they include appropriate references to dementia as a condition which can give rise to impairments that can constitute a disability, and how disability legalisation and rights would apply to people with dementia.
- Meaningfully involve people with dementia and carers in the service developments and audits described above in accordance with PANEL principles.

Regulatory bodies

- Review and amend guidance on health and social care law and ethics to incorporate a social model of disability, disability legalisation and rights, as it applies to people with dementia and other cognitive, physical and sensory disabilities.

The general public and institutions or organisations that have contact with or speak about people affected by dementia

- Bear in mind that impairments caused by dementia may result in disability.
- Realise that the provisions contained in the United Nations Convention on the Rights of Persons with Disabilities also apply to people with dementia who experience disability.
- Strive to ensure that people with dementia have access, if and when needed, to the same rights and support as people with other disabilities.
- Be sensitive to and respect people’s preferences regarding the use of the label ‘disability’.
- Aim to offer support and consideration in response to a specified, apparent or suspected need.
- Avoid making it necessary for people to state that they have dementia or disability in order to access any support they may need.
- Involve people with dementia in the development of initiatives to ensure their full citizenship and equal social inclusion in the local and wider community.
- Look for ways to promote the full citizenship and social inclusion of everyone rather singling out people with dementia as a separate group (i.e. most if not all barriers are also encountered to some extent by people without dementia).
Portugal announces first dementia strategy

At the Alzheimer Summit 2017, Minister of Health for Portugal Adalberto Campos Fernandes announced the first dementia strategy for Portugal.

"With this new dementia strategy and its development, we hope to achieve, on the one hand, a level of integration and continuity of care amongst different levels of care and organisations, which define a health care pathway and ensure accessibility and the appropriate care at any point of the process.

Alzheimer Europe: At the Alzheimer Summit 2017 you announced a dementia strategy for Portugal. What do you hope will be achieved with the new strategy and how will it be developed?

Adalberto Campos Fernandes: With this new dementia strategy and its development, we hope to achieve, on the one hand, a level of integration and continuity of care amongst different levels of care and organisations, which define a health care pathway and ensure accessibility and the appropriate care at any point of the process. This pathway includes the definition of overall principles, safeguarding the entry of patients at any stage of the disease and emphasises home care in order to delay, for as long as possible, long-term institutionalisation which fosters dependence. More than ‘setting up’ a new specialised network, we must ensure existing resources are optimised and articulated in such a way that, when possible, they are integrated into channels which facilitate access to the required health care. Through counterparts assigned to each segment of the network – social or health care, primary, clinical and long-term, from the private, social or public sector – a functional coordination and facilitation is required. These will articulate with each other and with whoever assumes responsibility for the coordination of said strategy. The need for coordination increases when considering elderly people, who may present comorbidities and complex biological, psychological and social needs. The role of community based health care units is key in order to provide people-centred health care. Furthermore, these units, belonging to the primary health care network, must be fully articulated with social security services, as well as local municipalities. Health care pathways for people suffering dementia or cognitive deficit must ensure enough flexibility to adapt to each person, and his/her family needs.

On the other hand, with this integration and continuity of care we aim to ensure timely and accurate diagnosis, as well as access to appropriate..."
treatment. Moreover, we intend to safeguard all dementia patients’ wellbeing and uphold their fundamental rights.

This strategy will be developed through a joint effort from several Ministries, namely the Ministry of Health and the Ministry of Labour, Solidarity and Social Security. However, local strategies and commitments will deeply influence it. The role of Regional Health Authorities, Regional Social Security Authorities and Local Municipalities, allied to that of other Private Solidarity Institutions and Societal Organisations, is of major influence as well. An interinstitutional group responsible for drafting, implementing, monitoring and evaluating the Regional Plans will be created.

AE: What do you see as the biggest priority and the biggest challenge in the fight against dementia in Portugal?

ACF: Given the ageing of the Portuguese population, one of our biggest challenges is foster healthy ageing. Therefore, this strategy is integrated with the National Strategy for Healthy and Active Ageing.

As detailed in my previous answer and given the nature of our health care and social protection system, our main priority is to ensure access and integration and continuity of care to people who currently suffer dementia.

AE: How important is the Government’s relationship with Alzheimer Portugal?

ACF: Alzheimer Portugal is one of the institutions that has argued the most for the need of a strategy on care for people living with dementia whilst developing several public campaigns and experiences in providing care for these people. Thus, the Government requested its integration within the working group bringing forward the strategy. The Government intends to continue to rely on Alzheimer Portugal’s precious expertise to help us develop the said strategy.

AE: Is there a need for closer collaboration on dementia on a European or global level?

ACF: I am certain that such need exists. The magnitude of the challenges faced by this pathology demands that joint efforts are made in order to find multiple responses. These will be, necessarily, pharmacological, but also, organisational since new care models are required. New information and communication technologies can play a crucial part in this, as well as other new analysis strategies such as Big Data or Artificial Intelligence.

Adalberto Campos Fernandes

### AE members from Portugal, Spain and Malta participate in Alzheimer’s Summit

From 18 to 22 September the Summit on dementia was held in Lisbon with the support of the Queen Sophia of Spain Foundation. It was based on two main pillars: Social and Health Care Research organised by the National Reference Centre for Alzheimer’s and Dementia Carers (CREA) of Imserso and the Scientific Summit organised by the Center of Research in Neurological Diseases (CIEN) Foundation and the Center for Networked Biomedical Research in Neurodegenerative Diseases (CIBERNED).

At the Scientific Committee of the Social and Health Care Research, Alzheimer Portugal was represented by Maria do Rosário Zincke dos Reis who gave a presentation on the current situation of Alzheimer’s Disease in Portugal. Alzheimer Portugal also presented the document “Bases for the Definition of Public Policies in the Field of Dementia”, prepared by a working group which was created within the framework of the reform of the National Network for Integrated Continuous Care, including recommendations to the government on the main priorities to be included in the future National Dementia Plan. This document had already been in public discussion until 15 September and it was during this debate that the Minister of Health announced the fact that the Portuguese government will launch the national dementia plan.

The minister highlighted 3 important topics:

1. “intersectorial integration”;
2. improve early diagnosis;
3. access to treatment (drugs and rehabilitation).

Alzheimer Portugal’s President, José Carreira chaired a session on national plans which also included other members of Alzheimer Europe. Jesus Rodrigo, from Confederación Española de Alzheimer (CEFA) presented the situation in Spain and Charles Scerri, Board member of Alzheimer Europe from the Malta Dementia Society (MSIDA), gave an overview about main achievements in dementia at European level.”

“ The Government intends to continue to rely on Alzheimer Portugal’s precious expertise to help us develop the said strategy.”

Adalberto Campos Fernandes
World Health Organisation (WHO) launches the Global Dementia Observatory

On 7 December 2017, WHO launched the Global Dementia Observatory – a web-based platform which will track progress on the provision of services for people with dementia and for those who care for them, both within countries and globally.

WHO has developed the Global Dementia Observatory (GDO) in order to support countries in strengthening dementia-relevant policies and evidence-based service planning. It provides a framework and a set of indicators for data collection by countries, which can inform their policy development and service planning. The Global Dementia Observatory will also facilitate the timely sharing of information and translation of knowledge through a web-based interactive platform.

WHO officially launched the Global Dementia Observatory during a 2-day event in Geneva, Switzerland. Over 70 delegates from 45 countries across the world including people with dementia, policymakers, academic researchers, representatives of government, non-government and voluntary sector. Alzheimer Europe was represented by Jean Georges, Executive Director who presented the results from the European Dementia Monitor 2016 showing inequalities in access to care support across Europe and Helen Rochford-Brennan, Chairperson of Alzheimer Europe’s working group of people with dementia (EWGPWD) who made a speech on behalf of people with dementia.

The purpose of the meeting was to discuss how the GDO can be used to monitor progress in implementing the Global Action Plan on Dementia actions at national and global level in the following areas:

- Dementia epidemiology and costs
- Dementia as a public health priority
- Dementia awareness and friendliness
- Dementia risk reduction
- Dementia diagnosis, treatment, care and support
- Support for dementia carers

Dementia: number of people affected to triple in next 30 years

As the global population ages, the number of people living with dementia is expected to triple from 50 million to 152 million by 2050.

“Nearly 10 million people develop dementia each year, 6 million of them in low- and middle-income countries,” says Dr Tedros Adhanom Ghebreyesus, Director-General of WHO. “The suffering that results is enormous. This is an alarm call: we must pay greater attention to this growing challenge and ensure that all people living with dementia, wherever they live, get the care that they need.”

The estimated annual global cost of dementia is US$ 818 billion, equivalent to more than 1% of global gross domestic product. The total cost includes direct medical costs, social care and informal care (loss of income of carers). By 2030, the cost is expected to have more than doubled, to US$ 2 trillion, a cost that could undermine social and economic development and overwhelm health and social services, including long-term care systems.

A public health priority

In May 2017, the World Health Assembly endorsed the Global Action Plan on the Public Health Response to Dementia 2017–2025. It provides a comprehensive blueprint for action for WHO, policy-makers, and international, regional and national partners in a number of specified areas:

- increasing awareness of dementia and establishing dementia-friendly initiatives;
- reducing the risk of dementia;
- improving diagnosis, treatment and care;
- scaling up research and innovation; and
- providing support for carers of people living with dementia.
The main objective of the Global Dementia Observatory is to collate and disseminate data from Member States on key dementia indicators to strengthen countries’ ability to respond to the needs of people with dementia and their carers by strengthening relevant policies and legislation, supporting evidence based service planning, and facilitating capacity building across health and social care systems.

The Global Dementia Observatory will provide an effective mechanism for monitoring the implementation of the Global Action Plan on the Public Health Response to Dementia 2017-2025. It will function as a repository of best practices and policies, and a means of exchanging knowledge among Member States and other implementation partners. It will monitor the presence of national policy and plans, risk reduction measures and infrastructure for providing care and treatment. Information on surveillance systems and disease burden data is also included.

A number of Member States from the WHO European Region were actively involved in the initial development and data-collection phase of the Global Dementia Observatory, including France, Hungary, Italy, the Netherlands, Sweden, Switzerland and the United Kingdom. The idea is that, now other Member States will participate in the activities of the Global Dementia Observatory in a bid to strengthen national and regional efforts to address the public health and societal challenge of dementia.

Encouraging results in planning for dementia and support for carers

To date, WHO has collected data from 21 countries of all income levels. By the end of 2018, it is expected that 50 countries will be contributing data.

Initial results indicate that a high proportion of countries submitting data are already taking action in areas such as planning, dementia awareness and dementia-friendliness (such as facilitating participation in community activities and tackling the stigmatization of people living with dementia) and provision of support and training for carers, who are very often family members.

Of the countries reporting data so far:

- 81% have carried out a dementia awareness or risk reduction campaign
- 71% have a plan for dementia
- 71% provide support and training for carers
- 66% have a dementia-friendly initiative.

“This is the first global monitoring system for dementia that includes such a comprehensive range of data,” said Dr Tarun Dua, of WHO’s Department of Mental Health and Substance Abuse. “The system will not only enable us to track progress, but just as importantly, to identify areas where future efforts are most needed.”

The GDO online platform

- Data visualisation
- GDO indicators
- GDO reports
- Country profiles
- Policy briefs
- Regional interfaces
- Data repository
- Knowledge exchange
- iSupport
- mhGAP dementia
- Research prioritization
- DFI toolkit
- Risk reduction guidelines
- Publications, syst. reviews
- Policy guidance

World Health Organization

Alzheimer Europe
The GDO Action plan and key indicators

The seven strategic themes fully align with the seven action areas of the Global Action Plan on the Public Health Response to Dementia 2017–2025. These themes can be viewed as national goals or objectives which a country can use to introduce, improve or monitor dementia activities:

- Dementia as public health priority
- Dementia awareness and dementia friendliness
- Dementia risk reduction
- Dementia diagnosis, treatment, care and support
- Support for dementia carers
- Information systems for dementia
- Dementia research and innovation

All of these activities are recommended by WHO in the Global action plan on the public health response to dementia 2017–2025. The plan provides a comprehensive blueprint for action, in areas including: dementia awareness and dementia-friendliness; reducing the risk of dementia; diagnosis, treatment and care; research and innovation and support for dementia carers. It suggests concrete actions that can be taken by policy-makers, health and social-care providers, civil society organisations and people with dementia and their carers. The plan has been developed with attention to the importance of respecting the human rights of people with dementia and engaging them in planning for their care. Targets against which progress can be measured are included.

“I very much welcome the work that the World Health Organisation is doing in advancing the knowledge about dementia by developing the Global Dementia Observatory. This will allow for an exchange of knowledge and an opportunity to learn from one another.”

Helen Rochford-Brennan, EWGPWD

Appendix 5: Draft Global Dementia Observatory Data Framework

<table>
<thead>
<tr>
<th>Domains</th>
<th>Policy</th>
<th>Service delivery</th>
<th>Information &amp; Research</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Strategy / plan</td>
<td>Infrastructure</td>
<td>Dementia epidemiology &amp; cost</td>
</tr>
<tr>
<td></td>
<td>Legislation</td>
<td>Workforce</td>
<td>Risk factor prevalence</td>
</tr>
<tr>
<td></td>
<td>Guidelines</td>
<td>Treatments &amp; support</td>
<td>Research</td>
</tr>
<tr>
<td>Governance</td>
<td><strong>1: Dementia as public health priority</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Population</td>
<td><strong>2: Dementia awareness and friendliness</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individuals</td>
<td><strong>3: Dementia risk reduction</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>4: Dementia diagnosis, treatment, care and support</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cross-cutting principles</td>
<td><strong>5: Support for dementia carers</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>6: Information systems for dementia</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>7: Dementia research and innovation</strong></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Diagnosis and research

Just 14% of countries reporting data could indicate the number of people being diagnosed with dementia. Previous studies suggest that as many as 90% of people with dementia in low- and middle-income countries are unaware of their status.

The data also highlight the need for rapid scale-up of research. There have been some encouraging signs in funding available for investment in research for a cure for dementia in recent years, but much more needs to be done. Research is needed not only to find a cure for dementia, but also in the areas of prevention, risk reduction, diagnosis, treatment and care.

The Observatory will provide a knowledge bank where health and social care authorities, medical professionals, researchers and civil society organisations will be able to find country and regional dementia profiles, global reports, policy guidance, guidelines and toolkits on dementia prevention and care.

Information from the Observatory will greatly aid the development of national plans on dementia in more countries – which is a key call of Alzheimer Europe that all countries in Europe have a national dementia strategy or plan in place.
Comments from ADI on the launch of the GDO

In December 2017 Alzheimer’s Disease International (ADI) joined representatives from 45 countries at a meeting at the World Health Organization (WHO) for the launch of the Global Dementia Observatory (GDO). In development for two years, the launch of the GDO follows on quickly from the adoption of the Global action plan on dementia in May 2017, maintaining momentum and keeping the spotlight on dementia.

The multi-sectoral two day consultation was a first chance to review test phase data and to participate in more detailed discussions and workshops around key areas of the Global action plan. Attendees included people living with dementia, Member States, experts from organisations including ADI, Alzheimer Europe, OECD and World Dementia Council and the event gave participants an initial chance to engage with and review this web based data and knowledge exchange platform.

Following the import of test data from 22 countries the platform should become an ever increasing hub for national, regional and global data, supplemented by the latest epidemiological estimates and statistics.

The quality of captured data is vital and ADI believes that WHO, through the GDO, will need to consider technical assistance for Member States. Governments will need to ensure that resources are committed to tracking progress of their dementia plans. Civil society, in particularly national dementia associations, can assist in the promotion of the GDO, advise on the capture of data and also play a role in checking quality and robustness.

We look forward to the growth and further development of this vital resource.

Comments from Helen Rochford-Brennan, Chairperson, EWGPWD at the launch of the GDO

I very much welcome the work that the World Health Organisation is doing in advancing the knowledge about dementia by developing the Global Dementia Observatory. This will allow for an exchange of knowledge and an opportunity to learn from one another. I was very pleased to learn that the work Alzheimer Europe has carried out over the years has been recognised as important for the WHO observatory and that people with dementia, like myself, are increasingly being included in this kind of work. To conclude, I would like to congratulate the WHO on this initiative and on your openness to involve people with dementia. On behalf of Alzheimer Europe and the European Working Group of People with Dementia, I look forward to our continued collaboration on this very important work.
Council of Europe celebrates 20th Anniversary of the Oviedo Convention: relevance and challenges

For the occasion of the 20 years of the Oviedo convention, an international conference was organised by the Committee on Bioethics (DH-BIO) on 24–25 October 2017 in Strasbourg, under the auspices of the Czech Chairmanship of the Committee of Ministers.

The Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine (the Oviedo Convention) was formulated in 1997 by the Council of Europe. It was the first international legally binding instrument on the protection of human rights in the biomedical field.

The Convention consists of a preamble and 38 articles, organised into 14 chapters. It was conceived as a “framework instrument” which set up principles to prevent practices that would most seriously infringe on human rights and human dignity. It contains broad, general principles, which were intended to be developed in the years to come by additional protocols on specific issues. To date, the Council of Europe has developed four additional protocols (i.e. on the prohibition of cloning human beings, transplantation of organs and tissues of human origin, biomedical research and genetic testing for health purposes).

On the occasion of the 20 years of the Oviedo convention, an international conference was organised by the Committee on Bioethics (DH-BIO) on 24–25 October 2017 in Strasbourg, under the auspices of the Czech Chairmanship of the Committee of Ministers. During these two days, delegates heard presentations from a number of high-level profile speakers.

A highlight of the event was the signing ceremony of the Additional Protocol to the Convention on Human Rights and Biomedicine concerning genetic testing for health purposes by the Czech Republic. This additional protocol had been so far ratified only by 4 members of the Council of Europe and as such it will not come into force yet. As JUDr Radek Policar explained, the ratification by the Czech Republic was the last step needed to allow the Additional Protocol to become effective.

The opening session was chaired by Dr Beatrice Ioan (Chair of the Committee on Bioethics of the Council of Europe) and counted with the participation of JUDr Radek Policar (Deputy Minister for Legislation and Legal Affairs, Czech Republic), Ms Gabriella Battaini-Dragoni (Council of Europe Deputy Secretary General) and Ms Nada Al-Nashif, (UNESCO Assistant Director-General for Social and Human Sciences). Mrs Battaini-Dragoni Council of Europe’s Deputy Secretary General explained that the Convention was the “culmination of a complex process involving highly sensitive issues. A
process which would not have succeeded without constructive cooperation between all the relevant bodies and stakeholders”. She referred to the core principle of human dignity, protection of autonomy, protection of the integrity of the human body and the principle of justice and explained that it was the concern to protect these fundamental principles that had guided the drafting of the Oviedo Convention. These are still highly relevant today. She also reminded the audience of the need for constant vigilance in relation to any development that could pose a threat to fundamental human rights and the need to open this to public debate to “one that concerns all citizens”.

**History of the convention**

During the first day of the conference, there were keynote speeches on the history and principles that informed the development of this important Convention. Dr Quintana and Prof Honnefelder, both members of the drafting committee of the Convention, referred to the challenges the committee faced when writing it. In particular, for finding substantial agreement in many sensitive and uncertain topics. Dr Quintana explained that “the text of the Convention was the result of a pragmatic approach, without which we probably would not have managed to come up with a text at all”. He also referred to some other challenges, as for example, he mentioned that at the time of drafting of the Convention, the members of the committee were “not even in the position to foresee the creation of human embryonic stem-cell lines, nor the creation of ‘Dolly’ or the CRISPR-Cas technology and the multiplicity of possibilities it holds”, and thus, he said, prohibitions in specific cases should be time-limited, as the scientific and technological knowledge and practices will change and new and unforeseen possibilities of interventions may emerge, which may in turn impact on values and beliefs, and ultimately bring about paradigm shifts to the practical judgments in the area of bioethics and research ethics. He concluded that the role of bioethics should be to accompany progress in these areas and to foster public debate which could help to spell out the arguments and implications.

**Autonomy and consent**

Other topics addressed during the conference included: 1) autonomy, consent and privacy with particular attention to the challenges raised by the evolution of practices for children rights and older people; 2) equity of access to health care; and 3) new scientific and technological developments (i.e. genetics and genomics, new scientific and technological developments, brain technologies, information technologies and big data).

Challenges in the topics of autonomy and consent were comprehensively discussed by Dr Slokenberga, Dr Liefaard, Prof Carvalho and Prof Cherubini. Some of the relevant issues discussed included the concept changing/evolving capacity and the role of carers in providing consent. They referred to the need to “empower” and enable these groups to participate in research and see them as individuals with full human rights. Dr Liefaard advocated for a “children-friendly” biomedicine, concept which
could also be extended to older people. Discussions were also around the topics of vulnerability, risk and discrimination towards older people in general and in research. Important actions that need to be undertaken in this area included the development of cross-national standards for informed consent and for the assessment of capacity, harmonisation of legislation against ageism (also in research) and strengthening the inclusion of these groups in health research.

**Genetics and genomics**

In the area of genetics and genomics two different issues were addressed: i.e. issues related to sequencing and analysis and to the modification of the human genome. Pr Knoppers referred in particular to the issue of genetic discrimination and to how effectively articles 11 and 12 of the Convention could prevent it. She referred to a recent international study which revealed “a panoply of national approaches to prohibit, or, at a minimum, limit perceived or actual possible genetic discrimination in insurance”. Nevertheless, she added that a recent study indicated that legislation prohibiting genetic discrimination does not seem to (completely) alleviate fears of genetics discrimination, as such “fears seem to arise from pre-existing experiences of living with the social consequences of disease in the family”. Prof Montgomery reminded the audience that the concept of ‘the human genome’ is in fact quite ambiguous and not easy to define. He also explained that at the time that the Convention was drafted, the future of gene therapies was uncertain.

Twenty years later, somatic modification of the human genome has already occurred which has saved lives. He argued that “we need to refresh our understanding of article 13” of the Convention and advocated for the need of an “affirmative genealogy. He concluded that it would be important to consider whether experience now suggests a new articulation of the way in which the relationship between the advance of science and respect for human dignity calls for a response.

**Good governance**

Prof Winnickoff highlighted the important challenge of building good governance around innovation, especially in areas of emerging technology where science and technology are quickly evolving, norms and practices are changing quickly, and effects move across jurisdictions and levels. His speech was around the question of whether new human rights may be necessary to address issues raised by new neuro-technologies and explained that some academics have already advocated for the need of legal innovation and new human rights in this area given the new and important interests raised by new technologies. He highlighted great advances in this area such as the possibility of reading or intervening in the brain (with a therapeutic purpose e.g. for epilepsy or just as enhancement of the brain e.g. used in gaming communities). In here, there are relevant challenges around privacy, freedoms, risk and safety, health benefit and well-being. However, some of these challenges and interests are new as they are arising along with these new scanning/
Laurence Lwoff, Head of the Bioethics Unit of the Council of Europe said:

“The Conference was the occasion to celebrate the achievement that represents the Convention which had become a reference at European level but also at global level. But its objective was namely to examine the relevance of the principles laid down in the Oviedo Convention with regard to developments in the biomedical field and possible human rights challenges raised by such developments. This conference is particularly important as it will provide the basis for a midterm strategic action plan proposing a framework for the Council of Europe’s activities to address the human rights challenges raised by new technological developments in the field of biology and medicine and their impact on practices.”
Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) participates in 4th European Parliament of persons with disabilities

At the European Parliament the EWGPWD joined 600 persons with disabilities to discuss the right to vote and participate in political and public life, the next European disability strategy and the European Union being a global leader on inclusive sustainable development.

On 6 December, the 4th European Parliament of persons with disabilities (EPPD) took place in Brussels. More than 600 persons with disabilities from all over Europe attended the event and engaged in discussions about the right of persons with disabilities to vote and participate in political and public life, the next European disability strategy and the European Union being a global leader on inclusive sustainable development. During the EPPD, a manifesto on European elections 2019, a resolution on the next European disability strategy and an emergency resolution on the European Accessibility Act were adopted by the delegates. In the afternoon, delegates also discussed the Sustainable Development Goals and the importance of taking people with disabilities on board in their implementation. The Vice-Chair of the EWGPWD, Chris Roberts, was one of the representatives from different disability organisations to give a speech during this session.

The EPPD was co-organised by the European Disability Forum (EDF) of which AE is a member and the European Parliament. The President of the European Parliament, Antonio Tajani, and EDF President, Yannis Vardakastanis, opened the EPPD.

President of the European Parliament, Antonio Tajani, stated: “Our commitment to improve the lives of persons with disabilities is founded in our values as Europeans, including our attachment to freedom, equality and inclusion of all individuals in society. These values have to be translated into concrete actions, to enable every person to live an independent life, and to make sure that our society empowers everyone.”

A. Tajani, President, European Parliament
EDF President, Yannis Vardakastanis, stated: “Today we show a European Parliament close to its citizens. The EPPD is another milestone in the dialogue between EU elected representatives and citizens with disabilities. Throughout all EDF existence, the European Parliament has always been a strong and vocal defender of the human rights of persons with disabilities. Over the last two legislatures, the European Parliament promoted and protected the rights of persons with disabilities during legislation negotiations on the right to equal access to the internet, to transport or to independent living, as well as on the structural funds – in line with the provisions of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD).”

The EPPD gave European citizens with disabilities, both leaders and grass-root activists a unique opportunity to talk with Members of the European Parliament (MEPs) and high level representatives of other EU institutions about their human rights. This year the topics under discussion were: the right to vote and participate in political and public life, the European disability strategy 2020–2030 and the European Union (EU) being a global leader on inclusive Sustainable Development.

During the EPPD, a manifesto on European elections 2019, a resolution on the next European disability strategy and an emergency resolution on the European Accessibility Act were adopted by the delegates. During the afternoon session when delegates discussed the sustainable development goals and the importance of taking people with disabilities on board in their implementation Chris Roberts Vice Chair of the EWGPWD, was one of the representatives from different disability organisations to give a speech (see following page).
“My name is Chris Roberts, I was diagnosed with mixed dementia, Alzheimer’s and vascular five years ago. I represent the European Working Group of People with Dementia, which has been established since 2012. Dementia ‘IS a disability’, it is covered by, disability discrimination legislation. And at a domestic level, that means the Equality Act. At an international level, the equivalent is the Convention on the Rights of Persons with Disabilities (the CRPD). Both these laws talk about reasonable adaptations and adjustments, that can be made to ensure that people with dementia and other disabilities, are included and not excluded, ‘doing with and not for’. We need to make sure that the public services that do exist, are more enabling to help reduce the anxiety and agitation, that people affected by dementia, feel on a daily basis, and not to forget their families that are also affected. A quarter of people in hospitals and prisons have a form of dementia: what are we doing to make their experience easier? And yet despite dementia being recognised as a disability, good practice is not widespread or fully promoted as the law dictates, any training and awareness that does exist to try and improve this is very weak, tokenistic and inconsistent. People affected by dementia still face numerous challenges in realising their rights and encounter continual stigma and prejudice. There still remains a total lack of understanding about the dementias, as well as multiple discriminations on so many grounds, including age and gender, compounded with bad care, abuse and, mostly non-existent services. The legislation which is there to protect and uphold our rights has been poor, variable, and in some European countries, has been trampled on, or even worse, not considered at all! People affected by dementia are not receiving the protection that these laws are supposed to provide. Dementia is mostly, until the late stages, a hidden or invisible illness. So perceptions of this illness and what the person requires often prevails over the person’s actual needs, which can vary hugely depending on the type of dementia, the environment, the country they reside in, their age, and the support around them (or lack off). Furthermore, the ‘social model of disability’ which should be applied to dementia, is continually overridden by the “medical model”. This must change! And finally, I would like to say thank you to all of you that have stayed to listen and have “not left us behind”!

‘Nothing about us without all of us’
EU4HEALTH Campaign calls for continued future health collaboration in Europe

European Union (EU) health collaboration is vital for Europe’s future. Alzheimer Europe is amongst a growing number of organisations who have expressed concern about the state of health in the EU.

A joint campaign led by the European Patients Foundation (EPF) and European Public Health Alliance (EPHA) is calling for reassurances from the European Commission (EC) that in the future health will continue to be a priority in the European Union (EU) and that the European Commission’s DG SANTE will not be closed and a Health in All Policies (HiAP) approach taken by the European Commission. Alzheimer Europe fully support the “EU4Health” campaign and to date are amongst over 230 organisations who have signed the petition calling on the EC to step up coordinated EU action to tackle cross-border health challenges.

At the beginning of this year on 18 January, European Commission’s President Jean-Claude Juncker appointed six members to the Task Force on Subsidiarity, Proportionality and “Doing Less More Efficiently” to explore and identify which policy areas should be addressed at a different level (national, regional, local).

Despite the clear European added value, there is a growing concern that EU Health policy action and health collaboration might be one of the areas this task force decides to de-prioritise at European level. The task force is under the Chairmanship of First Vice-President Frans Timmermans and will report to the President by 15 July 2018.

EU: Do More For Health! The future of Health in Europe: What do we want?

In March 2017 European Commission President Jean Claude Juncker presented a white paper on the future of Europe, outlining 5 scenarios. In these scenarios, the option to “do less” on some policy areas is contemplated. It is feared by health stakeholders and civil society that this could lead to less EU action on health after 2020. The European Public Health Alliance (EPHA), the European Patients’ Forum (EPF) and a coalition of organisations teamed up to express their concerns in a letter to European Commission President, Jean Claude Juncker.

Alzheimer Europe and 38 other organisations representing EU health stakeholders addressed the joint letter to Jean Claude Juncker, President of the European Commission, expressing grave concern about the future of health in European policies and programmes. The letter ends with a request for a meeting with President Juncker in order to explore the issues in more detail and agree a viable way forward.

Health matters: let’s make our voices heard!

Based on the work developed under the #EU4HEALTH Campaign since last year, EPF and EPHA who are leading the campaign and a group of public health NGOs including Alzheimer Europe have developed some key asks to forward to the task force headed by Timmermans.

The message the #EU4HEALTH Campaign want to get across is clear: European health collaboration has a lot of added value. We want continued EU policy action on health with strong political leadership from the European Commission on health, including a Commissioner and Directorate General on Health.

Zoltan Massey from EPHA says, “There has never been a stronger case, or a more vital moment for Europe, to commit to working together on health which is so close to citizens’ hearts. The EU can offer a vision of the future which puts its people in the centre and makes a tangible difference to their lives. Let’s hope that remaining actions of the outgoing Juncker Commission during the current political mandate will speak louder than a thousand words and will ensure strong EU policy on health”
A positive vision for EU Health action

MEPs call for continued EU engagement in healthcare

More than 70 Members of the European Parliament (MEPs), from all major political groups, have signed a statement expressing their deep concern about the future of healthcare policy in the EU, in the wake of the publication of the “White Paper on the Future of Europe” in 2017.

The statement was put forward by MEP Andrey Kovatchev (Bulgaria) as a follow-up initiative to a recent event of the MEP Interest Group on Access to Healthcare and the Patient Access Partnership (PACT), entitled “Future Scenarios for the EU: What role for Healthcare?” which addressed the role of healthcare in future scenarios for the EU and the possibilities to strengthen and improve it.

The “Statement on the future engagement of the EU in healthcare”, dated 12 September 2017, calls for continued EU action in the field of health, as well as enhanced cooperation between EU Member States. The prospect of reducing EU engagement in the area of healthcare, as outlined in the White Paper, dated 1 March 2017, stands in stark contrast to the results of the Eurobarometer survey 2017, which showed an overwhelming demand (70%) for the EU to do more, not less, in this area (see opposite).

“We need to counter populist rhetoric and deliver on the expectations of European citizens”, the signatories of the Statement assert.

42 members of Alzheimer Europe’s European Alzheimer’s Alliance (EAA) support the statement calling for continued EU engagement in health

Alzheimer Europe is delighted to note that 42 of the 70 plus Members of the European Parliament (MEPs), who signed the “Statement on the future engagement of the EU in healthcare” are members of the European Alzheimer’s Alliance (EAA). Members’ expressed deep concern about the future of healthcare policy in the EU,

The 42 EAA signatories are (in alphabetical order):
- Georges BACH (Luxembourg), Vilija BLINKEVIČIŪTĖ (Lithuania), Biljana BORZAN (Croatia), Cristian-Silviu BUŞOI (Romania), Soledad CABEZÓN RUIZ (Spain), Nessa CHILDERS (Ireland), Deirdre CLUNE (Ireland), Carlos COELHO (Portugal), Tanja FAJON (Slovenia), Elena GENTILE (Italy), Nathalie GRIESBECK (France), Françoise GROSSETÊTE (France), Marian HARKIN (Ireland), Brian HAYES (Ireland), Anneli JÄÄTTEENMÄKI (Finland), Karin KADENBACH (Austria), Manolis KEFALOLOGIANNIS (Greece), Seán KELLY (Ireland), Andrey KOVATCHEV (Bulgaria), Merja KYLLÖNEN (Finland), Marian-Jean MARINESCU (Romania), Costas MAVRIDES (Cyprus), Linda McAVAN (United Kingdom), Mairead McGUINNESS (Ireland), Miroslav MIKOLÁŠIK (Slovakia), Elisabeth MORIN-CHARTIER (France), Dimitrios PAPADIMOULIS (Greece), Alojz PETERLE (Slovenia), Sirpa PIETIKÄINEN (Finland), Marek PLURA (Poland), Sofia RIBEIRO (Portugal), Paul RÜBIG (Austria), Olga SEHNAŁOVA (Czech Republic), Igor ŠOLTÉS (Slovenia), Bart STAES (Belgium), Ivan ŠTEFANEČ (Slovakia), Romana TOMC (Slovenia), Ivo VAJGL (Slovenia), Lambert van NISTELROOIJ (Netherlands), Hilde VAUTMANS (Belgium), Julie WARD (United Kingdom), Renate WEBER (Romania).

Alzheimer Europe congratulates all 42 of these MEPs, as well as their peers who have also signed the statement, for taking action to ensure the health and wellbeing of all citizens remains a priority for the EU in the future.

There has never been a stronger case, or a more vital moment for Europe, to commit to working together on health which is so close to citizens’ hearts. The EU can offer a vision of the future which puts its people in the centre and makes a tangible difference to their lives. Let’s hope that remaining actions of the outgoing Juncker Commission during the current political mandate will speak lauder than thousand words and will ensure strong EU policy on health.

Zoltán Massay-Kosubek, European Public Health Alliance
FULL STATEMENT

Statement on the future engagement of the EU in healthcare

We, the undersigned Members of the European Parliament, are deeply concerned about the prospect of reducing EU engagement in the area of healthcare outlined by some of the scenarios in the “White Paper on the Future of Europe”. European integration has brought considerable benefits for the health of Europeans. This cooperation must be sustained to ensure that citizens across the EU enjoy equality of opportunity to receive quality health care and services in their country. Patients should not pay the cost of non-Europe in healthcare!

We believe that Europe is about more than a common market and currency. Strengthening the economic foundations of the European project is undoubtedly crucial, but it remains merely a means of achieving prosperity in the Union. Health is a precondition for prosperity and the ambitious European agenda for growth and jobs cannot be achieved without healthy European citizens.

European health systems are struggling to respond to the pressing challenges of ageing populations, strained health budgets and rising levels of health inequalities. These challenges transcend national borders and call for common European solutions. Ignoring them would not only be economically inefficient, but also politically dangerous. Wide disparities in health undermine social cohesion and foster political discontent, thus hindering cooperation and the process of European integration.

In order to secure the future of the European Union we need to counter populist rhetoric and deliver on the expectations of European citizens. Recent Eurobarometer surveys have consistently shown that around 70% of Europeans wish to see more EU engagement in the area of health. We call for continued European Union action in the field of health and enhanced cooperation between EU Member States as a prerequisite for the sustainable development of our Union.
European news in brief

Alzheimer Europe takes a look at some top EU stories in brief

**European Union’s Health programme publishes list of organisations receiving Operating Grant**

Alzheimer Europe was one of the 13 organisations which will be awarded a Framework Partnership Agreement (FPA) from the European Union’s health programme to cover our operations for the years 2018–2021. Thanks to this support, we will be able to continue key initiatives such as our European Working Group of People with Dementia, our European Dementia Ethics Network and our Annual Conferences.

**European Pillar of Social Rights**

On 17 November in Gothenburg, Sweden at the Social Summit for Fair Jobs and Growth, the Pillar was signed by Jean-Claude Juncker, President of the European Commission, Antonio Tajani, President of the European Parliament and Jüri Ratas, Presidency of the Council of the European Union.

The Pillar of Social Rights is about delivering new and more effective rights for citizens. It builds upon 20 key principles, structured around three categories:

- Equal opportunities and access to the labour market
- Fair working conditions
- Social protection and inclusion.

Many of the 20 rights/principles in the proposal are very relevant and important to older people and people with dementia and their carers in particular:

- The right to work-life balance is already a legislative proposal with five days per year of paid leave to care for dependent relatives. The proposal gives carers the right to request flexible working arrangements, like reduced or flexible working hours or flexibility at work. The proposal is currently being debated by the EU Council and the European Parliament as part of the legislative process.

- The right to long-term care states that everyone has the right to affordable long-term care services of good quality, in particular home-care and community-based services.

**European Commission publishes mid-term evaluation of the 3rd Health Programme 2014–2020**

The mid-term evaluation of the first three years of the implementation of the third Health Programme 2014–2020 reveals that the European Commission has made major progress towards reaching the programme’s objectives.

Most notably, the Commission has helped to:

- establish 24 European Reference Networks for rare disease patients who can now benefit from the best expertise available in Europe,
- increase Member States’ capacity-building potential to respond to outbreaks such as Ebola and Zika viruses,
- and strengthen the EU’s migration policy by helping EU countries cope with the health needs of migrants and refugees and training health professionals and support staff.

The Commission is also continuing its collaboration with the OECD and the European Observatory on Health Systems and Policies on the State of Health in the EU cycle aimed at strengthening
European Commission publishes State of health in EU report

On 23 November the European Commission published the State of Health in the EU in 2017 with 28 country health profiles and overview report. The reports were prepared in cooperation with the OECD and the European Observatory on Health Systems and Policies. The findings show that Europe needs to focus on being more effective, accessible and resilient

Key findings

• Health promotion and disease prevention pave the way for a more effective and efficient health system. Aside from the unbalanced investments in prevention, social inequalities need to be tackled, as illustrated by the differences in cancer screening or physical activity between people with higher and lower income and education.
• Strong primary care efficiently guides patients through the health system and helps avoid wasteful spending. 27% visit an emergency department because of inadequate primary care. Only 14 EU countries require primary care referral for consulting a specialist; 9 other countries have financial incentives for referrals.
• Integrated care ensures that a patient receives joined-up care. It avoids the situation we currently see in nearly all EU countries, where care is fragmented and patients have to search their way through a maze of care facilities.
• Proactive health workforce planning and forecasting make health systems resilient to future evolutions. The EU has 18 million healthcare professionals, and another 1.8 million jobs will be created by 2025. Health authorities need to prepare their workforce for upcoming changes: an ageing population and multimorbidity, the need for sound recruitment policies, new skills, and technical innovation.
• Patients should be at the centre of the next generation of better health data for policy and practice. The digital transformation of health and care helps capture real-world outcomes and experiences that matter to patients, with great potential for strengthening the effectiveness of health systems.

Vytenis Andriukaitis, Commissioner for Health and Food Safety, said: “Spending only 3% of our health budgets on prevention, compared with 80% on the treatment of diseases, is simply not enough. We need better access to primary care so that the emergency room isn’t people’s first port of call. And we need to enshrine health promotion and disease prevention into all policy sectors to improve people’s health and reduce pressure on health systems. These are just a few of the diagnoses coming out from our 2017 State of Health in the EU report. By offering comprehensive data and insights, we aim to support national health authorities in tackling the challenges and in making the right policy and investment choices. I hope they will make good use of it.”

Amsterdam selected as new seat for European Medicines Agency (EMA)

On 20 November the EU 27 ministers selected Amsterdam, the Netherlands, as the new seat for the European Medicines Agency (EMA). The selection took place in the margins of the General Affairs Council (Article 50), in accordance with the procedure endorsed by the EU 27 heads of State and Government on 22 June 2017. The European Medicines Agency (EMA) currently based in the UK, needed to be relocated in the context of the UK’s withdrawal from the EU.

During a meeting of the Patients’ and Consumers’ Working Party of the European Medicines Agency on 22 November, the Agency’s Director Guido Rasi updated the participants about the decision of the Council to move the Agency to Amsterdam. Prior to the decision, the Agency had stayed neutral, but highlighted the potential impact of the new location on staff retention and business continuity. Staff surveys had indicated that the Agency could lose significant numbers of EMA and even a move to Amsterdam could result in staff losses of up to 19%. Guido Rasi also highlighted that there was no indication as to the role which the United Kingdom would play in the future European regulatory system and whether the UK would stay involved in future EMA activities.
Alzheimer Europe welcomes new members from Montenegro

At our 2017 AGM our membership voted unanimously in favour of accepting NVO Futura Montenegro as a new provisional member

NVO Futura Montenegro, is a newly founded association. The primary goal of NVO Futura is to provide information on all aspects of dementia as well as providing assistance and education to all who have contact with people with dementia, especially family members. The organisation also aim to raise public awareness about Alzheimer’s disease and advocate that early diagnosis is very important. Their ultimate goal is to provide long-term answers to help people with dementia and to promote and provide better treatment for people with dementia as well as provide day care centres to help families take care of the person with dementia.

There is no accurate statistical data on dementia in Montenegro, but it is estimated that 5–7% of 60-year-olds have a form of dementia, and they make up about 15% of the total population (taking the average total number of people with dementia in Montenegro to about 6,000). At the moment, we have the lowest level of financial support. The costs of treatment for a person’s illness in Montenegro are very high and in the public health institutions there is still no complete diagnostic treatment.

As a key motivation for the establishment of this association, apart from the statistics above, there is also a direct link between some of NVO Futura founding members who have a family member living with dementia and who have gone through all phases of the disease including nursing the patient and coping with all the problems and difficulties that AD brings. The team consists of members, Alma Orahovac, Zeljko Krgovic, Djurdjija Stjepkovic-Ivanovic, Biljana Pavlicic, Neda Dabovic and volunteers, as well as two neurologists, Dr Ilija Stolic and Dr Miljen Debeljovic, a psychologist, Tijana Vukovic, a pharmacist, Dr Vera Dabanovic and a surgeon, Dr Vesna Lakusic.

There is no accurate statistical data on dementia in Montenegro, but it is estimated that 5–7% of 60-year-olds have a form of dementia, and they make up about 15% of the total population.

Alma Orahovac
Current projects

NVO Futura is currently working on a project called “Dementia counselling”, which includes elderly people with dementia, their families and caregivers.

Main activities:
- Creating and raising awareness, both in patients and their families and caregivers, informing individuals and the community about the problems and difficulties caused by Alzheimer’s disease or dementia,
- helping to provide a care giving while providing the necessary medicines and personal hygiene products, providing guidelines to families through theoretical and practical lectures, creative workshops, brochures,
- more closely to familiarise themselves with dementia, stages, causes and proper treatment and treatment of patients, collaboration with competent institutions, rising awareness within the community and pointing at problems, making a database,
- through counselling, we will make possible meeting and having a conversation with professionals (neurologists, psychologists, psychiatrists, sociologists, internists),
- establishing the website, creating the possibility to report the case on dementia in the family, procurement,
- distribution of brochures intended for families with dementia which contain the necessary information on the nature of the disease,
- recommendations for families and caregivers, in order to help them in some way, provide support,
- organising expert meetings.

During 2018 a room for a counsellor will be established, where the citizens and families of the patients will be able to contact NVO Futura but for now the site www.nvofutura.me is active through which they can be informed and registered and report the case of a person with dementia (the data is anonymous).

Positive results through activities and lectures

On 21st September, to celebrate World Alzheimer Day in the centre of Podgorica the capital city of Montenegro. NGO FUTURA organised an information desk, where they shared the brochure “Recognize the 10 signs of Alzheimer’s disease”. NGO FUTURA interviewed the public and offered them the clock drawing test as an initial screening test, this was done in the presence of a professional neurologist who followed the course of the test and provided the public with useful follow up information. From the interview and the survey, it was possible to conclude that the citizens of Podgorica and generally from Montenegro, are poorly informed about dementia and the treatment of patients, which is why NVO Futura has planned to organise further lectures and workshops.

A lecture was held in September where the attendees could hear more about Alzheimer’s disease, establishing diagnosis, testing and drug therapy used in the treatment of dementia sufferers, and we had a great number of visitors. The doctors who held lectures, after their presentations, responded to the questions asked by the participants.

In conversation with citizens and during lectures, NVO FUTURA has found that families are most interested in how to take care of a sick family member, their home safety, how to behave in cases of aggression and violence, as well as depressive moods and in to know at what point the person with dementia is incapable of independent life.

To follow up the intensive workshops and lectures more are scheduled in nursing homes for old people, local communities and clubs of senior people.

NVO Futura has great support from the Capital City of Montenegro and its mayor Mr Slavoljub Stjepovic, the Government, the Health Insurance Fund of Montenegro and also received a good reception in conversation with the Director of the Public Health Institution in Podgorica – Dr Nebojsa Kavaric. Both have recognised the importance and role of the NVO sector when the health system is in question and have signed a memorandum on joint cooperation and work.

“NVO Futura has found that families are most interested in how to take care of a sick family member, their home safety, how to behave in cases of aggression and violence, as well as depressive moods and in to know at what point the person with dementia is incapable of independent life.”

Alma Orahovac
Young researchers rise to the dementia challenge in European research

Young researchers are involved in a number of European research projects or networks in which AE is partnering. We asked representatives of three initiatives to tell us more about the involvement of young researchers.

World young leaders in dementia (WYLD)
WYLD was formed from the series of legacy events following the G8 summit on dementia in 2013. Since then WYLD has continued to develop a global network, becoming the world’s leading organisation for people under 40 working in the field of dementia. The aim is to bring together young professionals working across disciplines and across borders to develop innovative approaches to the challenges faced by people with dementia and their families and caregivers. From its inception WYLD has been particularly strong in Europe, supported and encouraged by Alzheimer Europe.

WYLD present their work at the 27AEC
WYLD was delighted to actively take part in the 27th Alzheimer Europe conference (27AEC) in Berlin last year. During the conference WYLD members were very busy actively tweeting and blogging WYLD members also presented their own work during the conference poster sessions. One such person was occupational therapist Verena Tatzer from Austria who presented work from her recently completed PhD thesis. Her project examined how activity and occupation promote the experience of identity from the perspective of people with dementia living in long-term care. She told us: “The conference is a great possibility to meet lots of people and the poster presentations are an important part and offer a good format to discuss research with other experts in more depth. This is especially useful in the course of doing the PhD but also afterwards.”

The future of dementia-friendly communities
At the conference the WYLD network also ran a workshop on the future of “dementia-friendly communities”. WYLD used the workshop to explore new
and innovative ways in which dementia-friendly communities might be taken forward in the future, particularly by young people. Olivier Constant was one of the co-organisers of the workshop and presented his work as part of the Flanders Centre of Expertise on Dementia: “It was an honour to be part of the WYLD workshop in Berlin and explain the Flemish strategy with a clear focus on dementia-friendly communication and empowerment. I strongly believe that people with dementia can teach us something of great value for all ages: learning to cope with vulnerability and accepting that imperfection is also good enough. It was fantastic to see lots of inspiring ideas being shared during our workshop with participants from all over Europe on which we’ll build further with WYLD members around the world.”

**WYLD is growing with new members and partners**
The conference was not only a fantastic opportunity to meet up with old friends, but also to expand its network with new members and partners. In addition to strengthening the WYLD network within Europe, the meeting in Berlin provided an opportunity to build ties further afield. Mollie Checksfield from the USA, WYLD’s North America coordinator, attended the meeting allowing WYLD to link up with their network in the USA and Canada. Two members of WYLD from Japan, Takehito Tokuda and Yoshiyuki Kawano, were also on an extended visit to Europe encompassing the Alzheimer Europe conference. For WYLD, it was particularly valuable to hear their ideas on dementia-friendly communities in Japan where they have been well established for many years. The network look forward to developing these contacts further. With the strength of contribution from young people across Europe, WYLD are confident that the future of dementia cure and care is in safe hands.

---

**Synaptic dysfunction in Alzheimer disease (SyDAD)**

SyDAD is a European training network funded by Marie Skłodowska Curie Actions under the EU Horizon 2020 programme. The project is based on collaboration between four European academic institutions in Alzheimer’s disease (AD) research and two pharmaceutical companies, and includes the training of 15 PhD students of different nationalities. The programme aims to elucidate the mechanisms behind one of the earliest pre-symptomatic hallmarks in AD: the dysfunction and loss of synapses. Synapses are functional junctions that connect neurons and allow them to communicate. Interestingly, synapse dysfunction occurs early in AD and is the best correlate to cognitive decline. Due to their plasticity synapses are considered an important therapeutic target to restore brain function and stop the progression of AD. Therefore, the SyDAD programme is a research platform where innovation and collaboration meet together to educate a new generation of future researchers. The possibility to work in a stimulating and international environment with top scientists in the AD field will certainly benefit the career and progress of these young scientists.
SyDAD early stage researchers talk about their involvement in the SyDAD project

By enrolling in the SyDAD programme, Miguel Matias hopes to “become an expert in synapse dysfunction and AD by creating a network of contacts that will be valuable in the future”. Importantly, the SyDAD programme offers “the chance to find a project where the combination of basic and clinical research in AD are compatible”, mentioned Tomàs Jordà. Dario Cupolillo highlighted that “the ambitious mission of the SyDAD programme is to create a great world-wide group of young researchers, bound together by the same ultimate goal. Each SyDAD researcher will therefore take advantage of new ideas, mutual suggestions, shared competences and common resources”. Likewise, Giacomo Dentoni describes SyDAD as “a unique PhD programme for its international collaborative approach and its emphasis on high level bioscience training”. For Ana Ribeiro, SyDAD will “provide me with an outstanding opportunity to work with the great scientists in the field, working outside my own country and turning my PhD into an exciting work experience”.

On why it is important for young researchers to be involved in collaborative programmes such as the SyDAD one, Sebastien Therin said: “I highly recommend it to future students looking to embrace a scientific career, as it offers the possibility to work in a competitive international environment, among renowned academic institutes and pharmaceutical companies around Europe. The programme is also a great chance to establish a network and exchange points of view. Overall, my experience in SyDAD gave me the chance to meet different kinds of people from all over Europe and work side by side with dynamic young researchers that I can relate to. It’s a great way to share cultures and have a better understanding of your work but also the world we live in”.

Hazal Haytural and Una Smailovic talk about their participation at the 27AEC

SyDAD was represented at last year’s Alzheimer Europe’s conference in Berlin with an exhibition stand where SyDAD students were able to present their research and learn more about the care, social and political aspects of AD. At the conference, Hazal Haytural and Una Smailovic presented a poster and distributed leaflets. For Una, “Alzheimer Europe’s conference provided a unique opportunity for a comprehensive discussion on the real life impact of our research projects on the people living with dementia and their caregivers. During the conference, it was possible to discuss our research and explain why synapses are important in the disease progression with people who are directly or indirectly affected by dementia, as well as with clinical and care science researchers. We hope and strongly believe that our research on synaptic dysfunction in AD may facilitate the development of better treatments and interventions to prevent or delay the onset of dementia.”
European Prevention of Alzheimer's Dementia, (EPAD) Academy

The five-year EPAD project is a collaborative research initiative aimed at having a better understanding of the early stages of Alzheimer's disease and to prevent dementia before symptoms occur. It involves 38 organisations across Europe including universities, pharmaceutical companies and patient organisations.

On June 2017, the EPAD consortium launched the EPAD Academy which aims to efficiently leverage EPAD resources to foster and develop academic research capacity and output in Alzheimer's disease across Europe for maximum global impact.

Carlos Díaz, EPAD Academy Coordinator, reports the vision and goals for the EPAD Academy

Like many other public-private partnerships, EPAD gathers an amazing range of research expertise and experience. Most academic partners usually involve young researchers as they build their teams for their assigned tasks. However, the relationship of these early career researchers with the project itself is often very asymmetrical – they usually contribute in very significant ways to the project’s success (and some even become true project champions), but are typically isolated in ‘niches’ pertaining to their respective specific tasks and research areas, therefore benefiting relatively little from being exposed to such a unique world-class environment. The concept of the EPAD Academy originated from a realisation that EPAD was an ideal framework for young researchers (‘EPAD fellows’) to grow professionally, expand their views, enhance multidisciplinary perspectives and multiply the impact on their future careers – effectively helping to build the next generation of thought leaders in Alzheimer’s research. This however rarely happens organically; it would require a focussed effort to understand and fulfil the needs of young researchers, leveraging the resources that the project creates during its development for maximum effect.

The EPAD Academy activities are therefore expected not only to ensure proper exposure of young researchers to the scientific richness of the project and different environments outside their own labs, but also to provide them with training, help them to publish, design new research projects, use project data, build their networks, think outside the box, etc. Expanding the horizons of our ‘EPAD fellows’ will surely contribute to faster and better research on AD in the next decade.

Stina Saunders, ‘EPAD fellow’, talks about her involvement in the EPAD Academy

I am delighted to be a fellow at the EPAD Academy and to be given the opportunity to work alongside world class scientists, project managers and researchers. Before joining the EPAD Academy to undertake my doctoral research as part of a deliverable in the wider EPAD study, I had been involved in the trial delivery of the EPAD project. In true EPAD fashion, the EPAD Academy has been very inclusive and encouraging of new ideas to build a strong community of young academics. My PhD study is looking at the impact of diagnostic tests disclosure in the mild cognitive impairment population in memory clinics. I am excited to contribute with my research not only to the globally important EPAD study but also to represent the EPAD Academy. I look forward to the many activities planned for 2018 – the monthly webinars, workshops and collaborations ahead. I hope that the EPAD Academy will become a close circle of researchers who will be providing support and exchanging knowledge to nourish a new generation of academics in the field of dementia.

The EPAD project has received support from the Innovative Medicines Initiative (IMI) Joint Undertaking under grant agreement n° 115736, resources of which are composed of financial contribution from the European Union's Seventh Framework Programme (FP7/2007–2013) and EFPIA companies’ in kind contribution.
Dementia Action Alliance (DAA) campaign gives seldom heard groups a voice

In autumn 2017 ‘From Seldom Heard to Seen & Heard’ was launched bringing DAA members together for improved outcomes for people living with dementia and their carers who come from seldom heard groups

The Dementia Action Alliance (DAA) is an alliance of organisations across England that aims to connect, share best practice and take action on dementia. The DAA campaign raises awareness of the challenges faced by people with dementia from seldom heard groups.

These communities include:

- Lesbian, gay, bisexual and transgender + (LGBT+)
- Black, Asian, minority ethnics (BAME)
- Young onset dementia
- Prison population
- People living in rural communities
- People with learning disabilities.

DAA hosts roundtables to kickstart campaign

In June 2017, the DAA kick-started their campaign by holding roundtables on prisons, LGBT, and learning disabilities, which was attended by experts in the field and people affected by dementia. The attendees created a set of recommendations for people to implement to support people affected by dementia from these three groups and include:

- For people with a learning disability, conversations might be difficult, but health professionals need to tell the person the diagnosis and say the word dementia. The diagnosis needs to be understood and explained in a way that makes sense to the person.
- For people in prison, training needs to be available to help staff identify when a prisoner is presenting symptoms of dementia or other forms of cognitive impairment.
- For people in the LGBT+ community, organisations to create links with local services for the LGBT community and investigate opportunities for shared working, but also to increase signposting options if a resident / client would benefit from a service. Bringing in external services for talks and advertising their services may contribute to the creation of LGBT friendly communities.
Launching the campaign
Following these roundtables, the DAA officially launched ‘From Seldom Heard to Seen and Heard’ at an event in London in September 2017. This day saw people affected by dementia from seldom heard groups discuss the extra support that is required for these groups and what more they would like to see from people. In addition to the 3 aforementioned groups, delegates discussed BAME, young onset dementia, social deprivation, Irish, and Gypsies & Travellers.

Finding solutions for seldom heard groups
• Having African-Caribbean people living with the condition talking about it so that it is not perceived as ‘weird or exotic’.
• Speak to a South Asian patient to identify what a ‘person centred’ approach means for that individual.
• Increase awareness of people with young onset dementia.
• Target resources towards more deprived areas in the UK, to support those in social deprivation.
• Recognising emotional cost of migration of the Irish.
• Train Gypsies/Travellers as lay health trainers.
• To give weight behind the campaign, the DAA collected case studies from people with dementia from some of the groups discussed
• Karen who was born with Down’s Syndrome was diagnosed with Alzheimer’s Disease and staff have often felt their concerns have been dismissed because she has a learning disability and too often excuses have been made or other conditions used to mask what was the development of Karen’s dementia.
• Patrick feels that if he was straight, and had a heterosexual partner he would have been treated more positively by healthcare professionals.
• Tommy was significantly socially isolated within the (prison) unit. Other offenders found his behaviour irksome and attention seeking, because of this common lack of understanding of the reasons for his behaviour he was frequently shouted at or ridiculed.
• Peter lived alone in a council flat in a tower block. As services deteriorate in the community it seems we have more people like him presenting to hospital in crisis. This may have been different had there been a day centre, day hospital or community centre with transport for Peter that had good links with the carers and the GP surgery.
• Paddy an Irish Traveller was diagnosed with dementia in his late 50s. The family did not understand his behaviour and had never heard the terms dementia or Alzheimer’s. Having had difficulty registering with a GP, their concerns about not being listened to and being made to feel uncomfortable in doctors’ waiting rooms, they had little confidence that a doctor could help. When they eventually saw a GP, the jargon explanation made little sense and the information leaflets and websites were no help to the family who were mostly illiterate.

The campaign is still running and its objectives are to raise awareness of the challenges faced by people with dementia from seldom heard groups, influence system-wide change, and bring about organisational change. The DAA are asking members to pledge to take action and to share the results with the DAA, regardless of the seldom heard group they are supporting, members are also encouraged to share case studies which will be made available on the DAA website.

A testimonial from MacIntyre, one of the integral members in the campaign
“I’m extremely proud to have worked alongside DAA for their ‘Seldom Heard Campaign’ – they really have ensured that seldom heard groups are ‘seen and heard’. Thanks to the DAA, many of their members came together united in September, to pledge their support to improving outcomes for people living with dementia and their carers – many seldom heard groups were represented, such as lesbian, gay, bisexual and transgender + (LGBT+), Black, Asian, minority ethnics (BAME), prison population as well as people living with a learning disability. As we all know people from seldom heard groups face barriers to accessing good health and social care, which at time fails to meet their needs. The DAA highlighted the importance of the work we all need to do surrounding seldom heard groups and dementia. It was great for the DAA to organise and have many key industry figures join us from many organisations such as Public Health England, Royal College Nursing, and Alzheimer’s Society. Together we have the ability to make such a positive impact and ensure our voices continue to be heard. MacIntyre were thrilled to share our examples of best practice and to have such good feedback on the work we are doing. We look forward to continuing to work with the DAA, as our work certainly doesn’t stop now. A huge thank you to Kelly and the team at the DAA for calling for action and uniting us together”.

The campaign can be followed on Twitter @Dementia_Action using the hashtag #dementiaseenandheard
A look behind the headlines: ‘Vampire’ therapy

Dr James Pickett is Head of Research at Alzheimer’s Society, where he oversees the grants funding and research programmes, and regularly speaks to the media about latest research findings. Here he comments on reports in several UK newspapers that carried headlines discussing a ‘Vampire therapy’ as a potential way to treat Alzheimer’s disease.

AE: What is the ‘vampire therapy’ and does it hold any promise as a treatment?
The therapy involves taking blood plasma from younger people and infusing it into older people. The theory is that there is a factor – likely a protein or group of proteins – in the blood of young people that disappears as we age. Adding that factor back in might help to keep neurons alive and combat other signs of ageing.

The research that triggered these particular headlines was called the PLASMA trial. It involved 18 older people with Alzheimer’s disease who were given blood plasma infusions donated by younger people. The aim of the study was to make sure that this type of treatment was safe and well-tolerated by people with Alzheimer’s.

This work builds on previous findings in mice that generated lots of headlines a few years ago. For this, the researchers first used a technique called ‘parabiosis’, where the mice are surgically attached to each other so they share a circulatory system, including blood. When a young mouse was attached to an old mouse, the researchers found that the old mouse had improvements in memory. This finding was repeated when parabiosis was replaced with injections of blood plasma from the young mice into the old ones.

AE: Were the headlines right?
This particular technique has benefited from being given an eye-catching name, making it an easy sell to the newspapers. If you read a headline with ‘vampire therapy’ on it, you’re going to read on, aren’t you?

The headlines did use phrases like ‘could reverse ageing’, which is overstating things a little bit. While the original research showed that the so-called ‘vampire therapy’ could improve learning and memory in old mice, this new study in people didn’t dig that deep. They did do some tests of learning and memory but this was not the goal of the trial and the researchers did not see any improvements in these tests, as expected on a small safety trial.

One finding that the press release mentioned was that people receiving the treatment did have improvements in functional ability, which were described in the UK’s Daily Telegraph newspaper headline as ‘Vampire therapy’ helps Alzheimer’s patients pay bills and prepare meals again.’ This is accurate enough but doesn’t convey that it was only 18 Alzheimer’s patients.
What is interesting is that the headlines did deviate quite a lot from the original headline on the Stanford-issued press release about the story, which was “Stanford-based trial finds blood-plasma infusions for Alzheimer’s safe, promising.” Although more accurate, it’s maybe not as compelling as ‘vampire therapy’.

**AE: What might be the impact of this story in the scientific community?**

The main thing to note about this study was that it was small and short-term. It involved 18 people and lasted only a few months. Also, nine of the people involved were not blinded as to whether they were receiving the plasma or a control saline solution. Therefore we can’t really conclude anything about the improvements to functional ability as the study as it wasn’t big or long-term enough.

What the study does show is that the infusions are safe and can be tolerated by older people with Alzheimer’s disease. This means that the approach itself is not dangerous and researchers can work towards refining it and understanding what aspects of the young blood could be of most benefit.

Most of the studies that have looked into treating Alzheimer’s disease have so far looked at tackling single underlying causes such as the amyloid protein. Many treatments developed against amyloid have failed in clinical trials, so new approaches to tackling Alzheimer’s are always welcome. This is a highly innovative and novel approach, which is needed in tackling devastating neurodegenerative disease.

**AE: What are the next steps?**

The study was too small to be able to give us any real information about whether the plasma infusions can have an effect on functional ability or any other aspect of learning and memory for people with Alzheimer’s disease. However, it does show that the treatment is safe to use in people with Alzheimer’s, which is an important first step.

What we’ll need to see next is a larger, longer trial with proper blinding so we can begin to understand whether this really is an effective approach. Knowing more about what aspects of the young blood appear to be having an effect is also important as it could give more clues about the underlying disease mechanisms or help to identify potential treatment strategies.

If future studies work, then there is a well-established blood transfusion system in many countries so potentially this technique could be delivered to a large number of people. However, this sort of method does raise some questions. Would blood of young people remain free, altruistically given by the donors? Does the vampire headline conjure up images of a future dystopia where young people are forced to sell their blood to the highest bidder? We sincerely hope that this never happens, but for now it probably helped sell a few more newspapers.

“\What the study does show is that the infusions are safe and can be tolerated by older people with Alzheimer’s disease. This means that the approach itself is not dangerous and researchers can work towards refining it and understanding what aspects of the young blood could be of most benefit.\”

Dr James Pickett
Alzheimer Europe Conference opens under the theme “Care today, cure tomorrow”

The 27th AE Conference in Berlin opened on 2 October and brought together close to 750 participants from 42 countries including 39 people with dementia.

“We are delighted that we do not just speak about people living with dementia at our conference, but speak with them and fully involve them as speakers and in the planning process of our events.”

Iva Holmerová

The Alzheimer Europe Conference “Care today, cure tomorrow” was formally opened by Iva Holmerová, Chairperson of the organisation who welcomed close to 750 participants from 42 countries. The conference brought together 181 speakers, as well as 216 poster presenters to share their research, projects and experiences.

Together with Sabine Jansen, Executive Director of Deutsche Alzheimer Gesellschaft and Bernd Heise, a member of the German association’s Advisory Board of people living with dementia, they extended a special welcome to the 38 people with dementia attending the conference, as well as their carers and supporters:
“We are delighted that we do not just speak about people living with dementia at our conference, but speak with them and fully involve them as speakers and in the planning process of our events.”

Bernd Heise talked about his diagnosis of dementia and how when he realised he could no longer continue his job he found excellent support at the group in Munich. He expressed how useful the groups are not only helpful for people with dementia but also for relatives and friends to support and understand the disease. He said his dream is that one day radical research finds a cure which is in the near future so at least we here today can profit from it.

In his keynote presentation “Time is on our side”, Prof. Alexander Kurz from the Technical University in Munich gave an overview of the challenges and opportunities which future treatments for Alzheimer’s disease could raise. He expressed his hope that treatments currently under development will slow down the progression of the neurodegenerative process, particularly if administered at the early stage. Such a novel scenario could imply more years of life, more time and better capability to adapt to and cope with cognitive and functional impairment, more years spent at mild and moderate rather than at more advanced stages of the disease, and possibly even an escape from severe dementia and dependence. He called on Alzheimer associations, health care professionals and society at large to collaborate and assess how best to use this extra time provided by early diagnosis and novel treatments.

During the opening ceremony, dementia was highlighted as one of the key public health challenges at European, national and local level. Matthias von Schwanenflügel, Ministry for Family Affairs, Senior Citizens, Women and Youth and Regina Kraushaar, Ministry of Health gave an overview of the activities of Berlin and Germany to support people with dementia and their carers, raise awareness, combat stigma and support greater research in the field. The German “Allianz für Menschen mit Demenz” and the „Demenz Partner” campaign were showcased as examples of good practice.

The opening ceremony was brought to an end with a surprise rendition of a number of Berlin songs by the Board and staff of the conference co-host, the German Alzheimer’s association.
Snapshots from Berlin
#27AEC
European Working Group of People with Dementia contributes to success of AE conference

In Berlin, the group hosted a symposium and chaired parallel sessions on living well with dementia

Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) played a very active role and contributed in many different ways to the success of the AE Conference in Berlin.

On the day prior to the start of the conference, the EWGPWD met in Berlin. All members of the group were present in the meeting and the group welcomed a new member from Finland. During this meeting they prepared and rehearsed their contributions to the Conference, including the special symposium and their stand.

On Monday 2 October, members of the group participated in the AE Annual General Assembly, and its Chairperson, Helen Rochford-Brennan spoke about the relevance of involving people with dementia at national and European level. Then, the vice-chairs of the group together with the other members and AE staff, welcomed delegates with dementia registered for the conference and had a tour of the venue. This year 39 delegates with dementia participated in the conference – which is a new record!

On day two of the conference one of the main highlights was a symposium organised by the EWGPWD “Living well with dementia “We are still here, I am still... “”. During the symposium four people with dementia participated and shared their perspectives and lived experience.

Helga Rohra (Germany) spoke about: Employment I am still able to work. Amela Hajrič (Bosnia and Herzegovina), spoke about: Stigma, I am still experiencing stigma. Idalina Aguiar (Portugal), talked about: Social Media: I am still active on social media. Carol Hargreaves (Scotland, UK) spoke about Humour: I am still a person with a sense of Humour.
The positive message conveyed by all four speakers was that, although they meet with losses of competence and skills, they “continue to be themselves”, persons still able to contribute to society, still able to do things for themselves, still able to feel, laugh, work, take part in everyday life. In order to be able to do so, they felt that people with dementia need appropriate and timely support and a more inclusive society.

Helen Rochford-Brenan (Chair), and Chris Roberts (Vice-chair) together with his wife, participated in different plenary sessions on the topic of the impact of dementia in the family (see page 55) and Helen participated in the final roundtable discussion on the current and future research priorities (see page 58). Their speeches were very much welcomed by the audience and provided very valuable insights into their experiences of living with dementia. Also, Helga Rohra, member of the EWGPWD from Germany, and Jayne Goodrick (Chris’s wife), chaired parallel sessions on the topic of living with dementia and on dementia care training respectively.

The active participation of the members of the EWGPWD, and of delegates with dementia and carers and supporters, makes AE Conferences truly unique.

Alzheimer Europe and INTERDEM sign memorandum of understanding

At the AE Conference in Berlin, Alzheimer Europe and INTERDEM used the opportunity to sign a memorandum of understanding highlighting their willingness to collaborate in the memorandum, both organisations confirmed that they share a common vision of “changing perceptions, practice and policy in order to improve the quality of life of people with dementia and their carers” and affirmed the following rights of people with dementia:

- The right to a timely diagnosis;
- The right to access quality post diagnostic support;
- The right to person-centred, coordinated, quality care throughout their illness;
- The right to equitable access to treatments and therapeutic interventions;
- The right to be respected in their community as an individual with capacities and limitations.

INTERDEM is a pan-European network of researchers collaborating in research on and dissemination of Early, Timely and Quality Psychosocial Interventions in Dementia aimed at improving the quality of life of people with dementia and their supporters, across Europe.

Alzheimer Europe would like to thank all members of the EWGPWD and their supporters for their work and involvement at this year’s conference.
“Care today, cure tomorrow”

Alzheimer Europe held its 27th Conference on 2–4 October 2017 together with the German Alzheimer association

A focus on living with dementia and care approaches

The focus of the second day of the Alzheimer Europe Conference was on the experience of living with dementia and the importance of innovative care in supporting people with dementia and their carers.

The impact of dementia

On 3 October the first plenary session entitled “The impact of dementia on the whole family” was delivered by Chris Roberts, member of the EWGPWD and his wife Jayne Goodrick (Wales, United Kingdom). They shared their experience of receiving a diagnosis and how this diagnosis impacted Chris, his wife and his family and how they all had to learn how to “live with dementia”. They highlighted that dementia seriously challenges the whole family dynamic and relationships and can cause total breakdown, as well as a lot of guilt and blame.

They shared how they learned to overcome these challenges and how important their advocacy work on behalf of other people with dementia has become.

As a fitting conclusion, they highlighted: “We continue to do what we know best: be husband and wife rather than patient and carer”.

“Home care in dementia – relief for caregivers and support for care-receivers”

The second plenary speaker Prof. Elmar Gräßel from the University Hospital Erlangen Germany who gave a presentation on the importance of “Home care in dementia – relief for caregivers and support for care-receivers”.

Prof. Gräßel highlighted that more than 50% of carers are at risk of reduced physical health because of their caregiver role. He presented the range of support and respite services which are available for carers but stressed that carers need to be motivated to use these services. The implementation of non-pharmacological therapies in different settings was another important priority presented by Prof. Gräßel.

Dementia-friendly communities

The third speaker, Imogen Blood (United Kingdom) gave an update on “The European Joint Action on Dementia and its focus on dementia-friendly communities and initiatives”. She presented the findings and key conclusions of the report commissioned by the UK Department of Health. According to her, the focus of dementia-friendly community initiatives should be on removing barriers in order to promote the inclusion of people with dementia in the ordinary day-to-day life of their communities.

People with dementia involved in her research said that it was important for them to “continue to be me” by doing “normal” things. Having opportunities to make a contribution and having a say in the design, delivery and evaluation of dementia-friendly initiatives is also important.

“People with dementia don’t just want services. They want to go to the pub, to a football match, to chat and have a laugh.”

Imogen Blood
Key to the success of these initiatives is a broad alliance – a “social movement” which gathers and responds to the experiences and priorities of local people with dementia and their supporters, and builds on local resources and networks to raise public awareness and improve the physical environment.

**Ethical and legal considerations in the care of people with dementia at home**

The final session of the plenary was from Prof. Thomas Klie from the University of Freiburg (Germany) with his presentation on the “Ethical and legal considerations in the care of people with dementia at home”. Although life and care at home are preferred by most individuals, this exposes people with dementia and carers to particular strains. As a result, questions regarding human rights issues in care and fairness in the distribution of care tasks arise. To address these, Prof. Klie advocated for a “Caring Community” with a mix of informal, professional and voluntary help focusing on providing efficient care and case management.

**Dementia care in the 21st century**

The second plenary session entitled “Dementia care in the 21st century” started with an overview by Dr Anders Wimo from Karolinska Institutet (Sweden) on “The cost of dementia care”. According to him, 47 million people in the world lived with dementia (about 10.5 million in Europe) in 2015 and these numbers are expected to increase to 75 million in 2030 and 132 million in 2050. The socioeconomic impact is enormous with global costs estimated at USD 818 billion in 2015 of which 40% are due to informal care.

Prof. Knut Engedal from the University of Oslo (Norway) gave his presentation on “Care guidelines and national dementia strategies” and stressed that such strategies should be based on important ethical principles such as autonomy and dignity and the framework of person-centred care. In countries with strategies, the awareness of dementia in the public has been improved, more people with signs of dementia have received a diagnosis and more people have had access to services according to their needs. Another way of developing high-quality care for people with dementia is to establish national care guidelines, based on the best evidence from the literature. However, it is of importance that care guidelines and dementia strategies are anchored at national social and health authorities and that politicians are willing to finance public services that are recommended by the care guidelines and strategies.

Prof. Bob Woods from Bangor University (United Kingdom), presented top line results from a five country survey on “The experience of carers of a diagnosis of dementia”. Over 1,400 carers of people with dementia in the Czech Republic, Finland, Italy, the Netherlands and Scotland (UK) responded to a survey which was supported by an educational grant from Roche to Alzheimer Europe. The survey looked at first indications that led to carers seeking help, the role of different healthcare professionals in the diagnosis, existing barriers to diagnosis, the disclosure of the diagnosis to the person and carers and the provision of information and signposting to other services and post-diagnostic support. More details on this survey are available in a press release issued during the conference (full details can be found on page 9).

**Palliative care**

Prof. Lieve Van den Block from the Vrije Universiteit Brussel (Belgium) presented the “PACE project and its implications for palliative care for people with dementia” and stressed that the provision of high-quality palliative care should be a priority for nursing and care homes in Europe. The EU-funded PACE project studying palliative care in Belgium, the Netherlands, England, Finland, Poland and Italy found that the quality of end-of-life care for people with dementia in nursing homes and nursing home staff’s knowledge of palliative care must be improved.
The focus of the final day of the Alzheimer Europe Conference was on the diagnosis, treatment and prevention of dementia and on the important contributions of European research efforts to advancing these fields.

"Care today, cure tomorrow" call for increased dementia research funding and collaboration

Participants at AE Conference

The number of people with dementia could triple by 2015

Horst Bickel

Focus on prevention, timely diagnosis and innovative treatments

In his plenary presentation, Dr Horst Bickel from the Technical University of Munich (Germany) provided “An overview of current epidemiological trends in dementia”. He stressed that up to one third of dementia disorders could probably be prevented by controlling risk factors. The most promising in terms of prevention were a reduction of vascular risk factors (smoking, obesity and hypertension) and an increase in physical and mental activity. A number of studies suggested a secular trend towards a decline in dementia risk in Western countries.

Reducing dementia risk

Reducing dementia risk by targeting modifiable risk factors in mid-life: the lessons of the In-MINDD project” was also the focus of the presentation by Prof. Kate Irving from Dublin City University (Ireland). In-MINDD sought to take the best available evidence and integrate this within a communication and support tool to help communicate reliable and important messages to the public and the health and social care community via a website designed with this purpose. Although the intervention did not demonstrate a significant change in behaviour in participants, lessons were learned concerning the process of normalising new complex interventions into existing care and the role of technology in supporting behaviour change to support cognitive health. Prof. Irving concluded by calling for a balance between investment in prevention, care and cure.

Advances in Alzheimer’s diagnosis

Prof. Wiesje van der Flier from the VU Medical Centre in Amsterdam (Netherlands) focused on “Advances in Alzheimer’s diagnosis; implications for clinical practice?” Her positive assessment of the research over the past decades was that it had resulted in great progress in our knowledge of Alzheimer’s diagnosis. One of the challenges is how to combine the available information in a way that is both meaningful for the individual patient and doable for the individual doctor. According to Prof. van der Flier, there is room for shared decision making and improved communication between patients, carers and professional. E-tools may be of help for this purpose.

Are we getting closer to better treatments for Alzheimer’s disease?

The question “Are we getting closer to better treatments for Alzheimer’s disease?” was addressed by Prof. Frank Jessen from the University of Cologne (Germany). He highlighted the enormous challenge of developing a new treatment for Alzheimer’s disease, since, so far, all promising drugs for disease modification, but also new compounds for symptomatic treatment have failed to show clinical efficacy. Amongst the reasons for these failures, he cited difficulties with
treatment targets, mode of action and selection of patients. Despite these negative results, a number of important learnings were gained: Very early treatment and combination therapies are the upcoming next steps. Importantly, recent studies also showed promising results in the field of non-pharmacological interventions with regard to prevention of dementia. In addition, there is development in the treatment of behavioural symptoms at the stage of dementia.

**Identifying current and future research priorities**

A final round table brought together key stakeholders at a European level to discuss and identify current and future research priorities. Moderated by Sabine Jansen, the Executive Director of the German Alzheimer’s association, the panel included:

- Lutz Frölich (European Alzheimer’s Disease Consortium, Germany)
- Iva Holmerová (Alzheimer Europe, Czech Republic)
- Andreas Holtel (European Commission)
- Pierre Meulien (Innovative Medicines Initiative)
- Helen Rochford-Brennan (European Working Group of People with Dementia, Ireland)
- Winfried Teschauer (Deutsche Alzheimer Gesellschaft, Germany)
- Myrra Vernooij-Dassen (INTERDEM, Netherlands)

The participants highlighted the growing support for dementia research at both a national and European level, with a number of programmes including the Innovative Medicines Initiative (IMI), the Joint Programme for Neurodegenerative Diseases Research (JPND) and Horizon 2020 programme dedicating significant funds to all aspects of dementia research.

The need for a better coordination of these different programmes was discussed, as well as the importance of promoting a holistic approach to dementia research. Pierre Meulien presented the example of IMI which addresses all aspects of Alzheimer’s disease research, from knowledge creation to developing new treatments.

Andreas Holtel from the European Commission emphasised that beyond H2020, research on Alzheimer’s disease, dementia and neurodegenerative diseases in general will remain a prime focus, targeting the full breadth of research efforts from understanding the disease to implementation and public health research.

According to Winfried Teschauer, strengthening research in nursing and care sciences would support primary and secondary care. For the European Alzheimer’s Disease Consortium, the development
of sensitive and specific biomarkers for an early diagnosis of AD and other dementias, which can be used in general practice and the development of effective disease-modifying therapies for Alzheimer’s disease constitute priority areas for research.

Social health is a priority for the INTERDEM network and its chairperson Myrra Vernooij-Dassen expanded: “Social health, including social engagement is underused in prevention and treatment of dementia. Research could focus on its working mechanisms and on developing, evaluating and implementing interventions to enhance social health.”

Patient engagement and involvement in co-developing new strategies to combat Alzheimer’s disease was seen as critical to the success against the disease, according to Pierre Meulien, whilst Helen Rochford-Brennan said: “Every person with dementia has human rights, and should be entitled to receive information about research and, if willing, be enabled to take part in research on dementia. This gives us hope.”

The quick translation of research results into clinical practice was another important recommendation from the discussions and was highlighted by Iva Holmerová and Lutz Frölich: “Scientific advances have to be evaluated with respect to their clinical relevance and applicability in the practice of medicine”.

Echoing the motto of the conference, participants stressed the importance of “Care today, cure tomorrow” to ensure that we provide hope for the future for better treatment and prevention strategies, whilst recognising the need to improve the quality of life, support and care of people living with dementia today.

Auf Wiedersehen Berlin, Hola Barcelona 2018!
The conference closed with a video of Barcelona, the venue for next year’s conference.

See you next year in Barcelona! #28AEC

“People with dementia are experts by experience. An inclusive research approach is needed.”

Helen Rochford-Brennan
Congratulations to the winners of the poster awards

The Alzheimer Europe Foundation is pleased to present the winners of the poster award competition

Each year, following the conference the Alzheimer Europe Foundation awards prizes to the top four poster presentations as voted by conference participants. The winner for each day of the poster presentations (3 and 4 October) was awarded EUR 750 and the runner up for each day was awarded EUR 250.

Winners

Andrea Fabbo (Italy): The Rosemary diary: a tool for daily life
FABBO Andrea, BEVILACQUA Petra, BRUNO Patrizia, GUIDI Laura, PIRANI Alessandro

The “Rosemary diary” is a tool that can help elderly people, family caregivers and professionals such as general practitioner or nurses to plan and carry out daily activities like a game and to monitor information about the quality of care. This simple and pleasant “reminder agenda” is useful for older persons at risk of cognitive impairment to keep track of time and monitor daily tasks.

Siren Eriksen (Sweden): Living a meaningful life in relational changes: A systematic meta-synthesis of qualitative studies on persons with dementia
ERIKSEN Siren, HELVIK Anne-Sofie, JUVET Lene, SKOVDAL Kirsti, FØRSUND Linn Hege, GROV Ellen Karine

This project aimed to interpret and synthesise persons with dementia’s experience of lived relations with others are for health and well-being. When a person has dementia social relationships will be challenged and often changed. Considering how important relationships with others are for health and well-being, the challenges faced by persons with dementia, and the help and support they require, there was a need for a systematic review of the literature on this perspective.
There are school and handbooks written for people working in social care and health care. There is also available information and material for family carers. When the question came about information material, a handbook for the person affected, we had their experiences and shared their tips and advice. Before the book was finished it was also proofread by several persons affected by dementia. The book is now available in Swedish and is free of charge.

There are school and handbooks written for people working in social care and health care. There is also available information and material for family carers. When the question came about information material, a handbook for the person affected, we had their experiences and shared their tips and advice. Before the book was finished it was also proofread by several persons affected by dementia. The book is now available in Swedish and is free of charge.

**Runners up**

**Wilhelmina Hoffmann (Sweden): My handbook – when I have received a dementia diagnosis**

Hoffmann Wilhelmia, SAMUELLSON Ewa

**Francesca Neviani (Italy): “Tea for two”: a psychosocial intervention for PwD and their caregivers.**

NEVIANI Francesca, FABBO Andrea, MONZANI Martina, RICCHI Chiara, CONCARI Enio, LUPPI Emanuela, MARVERTI Elisa, CASELLI Luca, NERI Mirco, SELMI Laura, ALESSANDRA Camorani, SAOTTINI Michele, LIBBRA Maria Vittoria, BERTOLOTTI Marco

“Tea for Two” is a psychosocial intervention for people with dementia and their caregivers. Many studies have stressed the relevance of the caregiver in dementia care. Dementia causes a high burden for people with dementia and their caregivers due to challenging behaviour, disability, cognitive impairment. Psychosocial intervention has shown significant effects on reducing cognitive and behaviour impairment, caregiver burden and improving quality of life.

The Alzheimer Europe Foundation has awarded EUR 750 to each of the winners and EUR 250 to each of the runners up. Amongst the voting delegates, the Foundation also drew Isabelle Donnio (France) as the winner of a free registration for the Alzheimer Europe Conference in Barcelona.

The Alzheimer Europe Foundation would like to thank all of the conference delegates who voted and all poster presenters for their excellent contributions to the conference.
Facts and figures

- Over 96% of delegates would recommend future Alzheimer Europe Conferences to their colleagues.
- 88% of delegates found the opening ceremony and keynote lecture to be good/very good.

Attendees: breakdown by country

<table>
<thead>
<tr>
<th>Country</th>
<th>Attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>United Kingdom</td>
<td>137</td>
</tr>
<tr>
<td>Germany</td>
<td>132</td>
</tr>
<tr>
<td>Netherlands</td>
<td>65</td>
</tr>
<tr>
<td>Italy</td>
<td>54</td>
</tr>
<tr>
<td>Switzerland</td>
<td>40</td>
</tr>
<tr>
<td>Ireland</td>
<td>31</td>
</tr>
<tr>
<td>Norway</td>
<td>27</td>
</tr>
<tr>
<td>Sweden</td>
<td>26</td>
</tr>
<tr>
<td>Belgium</td>
<td>19</td>
</tr>
<tr>
<td>Iceland</td>
<td>19</td>
</tr>
<tr>
<td>Finland</td>
<td>17</td>
</tr>
<tr>
<td>France</td>
<td>17</td>
</tr>
<tr>
<td>USA</td>
<td>17</td>
</tr>
<tr>
<td>Austria</td>
<td>16</td>
</tr>
<tr>
<td>Denmark</td>
<td>15</td>
</tr>
<tr>
<td>Luxembourg</td>
<td>14</td>
</tr>
<tr>
<td>Spain</td>
<td>11</td>
</tr>
<tr>
<td>Portugal</td>
<td>11</td>
</tr>
<tr>
<td>Greece</td>
<td>8</td>
</tr>
<tr>
<td>Australia</td>
<td>7</td>
</tr>
<tr>
<td>Czech Republic</td>
<td>7</td>
</tr>
<tr>
<td>Slovenia</td>
<td>5</td>
</tr>
<tr>
<td>Romania</td>
<td>5</td>
</tr>
<tr>
<td>Malta</td>
<td>5</td>
</tr>
<tr>
<td>Israel</td>
<td>5</td>
</tr>
<tr>
<td>Poland</td>
<td>4</td>
</tr>
<tr>
<td>Hungary</td>
<td>4</td>
</tr>
<tr>
<td>Jersey</td>
<td>4</td>
</tr>
<tr>
<td>Japan</td>
<td>4</td>
</tr>
<tr>
<td>Canada</td>
<td>2</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>2</td>
</tr>
<tr>
<td>Slovakia</td>
<td>2</td>
</tr>
<tr>
<td>Faroe Islands</td>
<td>2</td>
</tr>
<tr>
<td>Estonia</td>
<td>1</td>
</tr>
<tr>
<td>Lebanon</td>
<td>1</td>
</tr>
<tr>
<td>Croatia</td>
<td>1</td>
</tr>
<tr>
<td>Turkey</td>
<td>1</td>
</tr>
<tr>
<td>Brazil</td>
<td>1</td>
</tr>
<tr>
<td>Hong Kong</td>
<td>1</td>
</tr>
<tr>
<td>Indonesia</td>
<td>1</td>
</tr>
<tr>
<td>Lithuania</td>
<td>1</td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>742</strong></td>
</tr>
</tbody>
</table>

Breakdown by category

- Academics/Researchers: 223
- Alzheimer association staff and volunteers: 185
- Health or social care professionals: 145
- Students: 52
- Industry representatives: 48
- Carers: 38
- People with dementia: 38
- Policy makers: 11
- Civil servants: 2

**Total: 742**
Our members are helping people with dementia and their carers in 34 countries