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EU Commissioner for Research, Science and Innovation highlights current and future European priorities for dementia research
Welcome
by Iva Holmerová, Chairperson of Alzheimer Europe

Alzheimer Europe

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Welcome

I am pleased to welcome you to the 28th edition of our Dementia in Europe magazine.

The first section highlights some of our recent efforts to ensure dementia remains a European priority, including our recent lunch debate in the European Parliament, which focused on dementia care in Europe. During the debate, Mario Possenti, General Secretary of Federazione Alzheimer Italia, told delegates about the impact that a diagnosis of dementia has on families and carers in his country. Professor Bob Woods of Bangor University then presented the results of a survey carried out jointly with Alzheimer Europe in 2017, to better understand how diagnosis affects carers’ experiences of dementia. Given the importance of the survey’s findings, we have also included a separate article exploring them. I would like to personally thank our lunch debate hosts MEPs Olga Sehnalová (Czech Republic) and Sirpa Pietikäinen (Finland), as well as Nessa Childers (Ireland) for their active participation and Prof. Woods for his leadership in the carers’ survey project.

Another area of our work is our involvement in European research projects and we are pleased to present the PARADIGM (Patients Active in Research and Dialogues for an Improved Generation of Medicines) project in this edition. This project has the ambitious aim of making meaningful patient engagement in the development of medicines a reality. Supporting people with dementia to take part in research, if they want to, is an important aspect of our work. We spoke to Chris Roberts, Vice-Chair of the European Working Group of People with Dementia (EWGPWD) and his wife Jayne Goodrick, about their experiences of taking part in a recent PARADIGM project consultation.

We are also actively involved in the European Prevention of Alzheimer’s Dementia (EPAD) project. EPAD reports on its significant progress in 2018, including the launch of its proof-of-concept platform and the development of new communication and branding tools.

Finally in this Alzheimer Europe section, our continued work in the field of ethics is featured, with Director for Projects Dianne Gove updating us on this year’s report topic: dementia and minority ethnic groups.

The Policy Watch section opens with an interview with Carlos Moedas, European Commissioner for Research, Science & Innovation since 2014. Mr Moedas gives us his perspective on providing European leadership in research and innovation. Also at European level, we take a look at the EU Joint Action on dementia, which is supporting collaboration among European countries to help improve the lives of people with dementia and their carers.

At national level, we have heartening news from both Portugal and Sweden. We speak to Alzheimer Europe Board member Maria do Rosário Zincke dos Reis about the June 2018 launch of Portugal’s national dementia strategy. We also hear from Sweden, where our Alzheimer Sverige colleague Karin Westerlund interviewed Minister Lena Hallengren about her Government’s decision to launch a strategy by 2022. Both Alzheimer Portugal and Alzheimer Sverige have been instrumental in bringing about these important developments and continue to work closely with their governments and other stakeholders to ensure people living with dementia are heard and represented at national level.

On a less positive note, France recently took the decision to stop the reimbursement of Alzheimer’s medicines. We talk to Pierre Krolak-Salmon, President of the French Federation of Memory Centres, about this controversial policy.

Finally, at global level, Elina Suzuki, Health Policy Analyst at OECD discusses the main findings of the 2018 OECD report on the quality of dementia care.

In our Dementia in Society section, we take a look at Patient and Public Involvement (PPI), with the UK’s Alzheimer’s Society discussing experiences of involving people affected by dementia in research. The Society also presents its Dementia Friends programme. Cormac Cahill, Communications Manager for The Alzheimer Society of Ireland presents his organisation’s research into and campaign for eating well with dementia, and in our Behind the Headlines article, Dr Anders Wimo from Karolinska Institutet looks at the challenges awaiting the introduction of new disease-modifying treatments for Alzheimer’s.

Our “special section” shines a spotlight on our Spanish members, CEFA (Confederación española de Alzheimer) and Fundación Alzheimer España (FAE), co-hosts of our 28th Alzheimer Europe Conference “Making dementia a European priority” #28AEC in Barcelona. We also hear from Ildefonso Fernández, a member of CEFA’s Expert Panel of People with Dementia (PEPA) who shares his personal experiences with dementia and highlights some of the political priorities of the PEPA group.

Finally, Adolfo Toledano from the Cajal Institute at the Spanish National Research Council and José Luis Molinuevo and Carolina Minguillón from the BarcelonaBeta Brain Research Center and the Pasqual Maragall Foundation give us an overview of Spain and Barcelona as important centres for Alzheimer’s research.

If you are reading this at the conference, I would like to welcome you to (hopefully) sunny Barcelona, where we will be focusing on policies and strategies, care approaches, care services, rights, dementia-friendly societies, genetics, prevention and treatment.

Enjoy the conference and our Dementia in Europe magazine!
European Parliament lunch debate focuses on dementia care in Europe

Alzheimer Europe and the European Alzheimer’s Alliance organised a lunch debate in the European Parliament which was hosted by MEPs Olga Sehnalová (Czech Republic) and Sirpa Pietikäinen (Finland).

On Tuesday 26 June 2018, an Alzheimer Europe lunch debate was organised in the European Parliament, focusing on the topic of “Dementia Care in the European Union”. The debate was opened by Olga Sehnalová MEP, who welcomed over 70 delegates from national Alzheimer’s associations, as well as members of the European Working Group of People with Dementia (EWGPWD) and representatives from different EU institutions, organisations and companies.

According to Olga Sehnalová, current estimates suggest that over nine million European citizens have a form of dementia and that the majority of people with dementia live at home, in the community or are cared for by their families. It was noted that caring for a loved one with dementia poses many challenges for families and carers and that for that reason, the lunch debate would look at dementia care in the European Union from the perspective of both carers and relevant areas of policy.

Caring for a person with dementia in Italy

Mario Possenti, the General Secretary of Federazione Alzheimer Italia highlighted the personal impact that a diagnosis of Alzheimer’s disease has on family members and carers not only on an emotional level (feelings of stress, depression, fear and anger), but also on a physical, social and economic level. He highlighted that many carers felt socially isolated due to the burden of everyday care, as well as the existing stigma associated with dementia and the conflict that sometimes arises between family members.

He stressed the need for greater information, training and support for informal carers in order to break the social isolation experienced by many of them, which requires the implementation of a series of specific interventions, fully embedded within the community, including psychosocial therapies and respite care services.

The experience of a diagnosis of dementia in five European countries

Professor Bob Woods, from Bangor University in Wales, presented the results of Alzheimer Europe’s carers’ survey (see pages 9–11 for additional details on the survey results), carried out in 2017 by Alzheimer Europe and Bangor University to better understand how diagnosis affects carers’ experiences of dementia. The study investigated the experiences informal carers had upon receiving a formal diagnosis in five European countries (Czech Republic, Finland, Italy, Netherlands and Scotland, UK).

Thanks to the support of participating organisations in each of the five countries, over 1,400 participants took part in the survey. The majority of respondents (82.8%) were women, had a median age of 57 and over half of them (51.5%) had college education or higher. Apart from the Netherlands, the majority of carers were the children (daughters) of the person with dementia. Interestingly, 7.8% of respondents reported that they were not in employment due to their role as a carer.

The majority of people with dementia who were being cared for were also women (61%) and had a median age of 77. According to the carers, the majority of people (53%) had been diagnosed at the mild stage of dementia, 36% had been diagnosed with moderate dementia and 4% with advanced dementia.

In addition, carers reported significant delays in receiving a diagnosis (overall time frame from point of a problem being noticed to the diagnosis being made); it took an average of 2.1 years to receive the diagnosis (ranging from 1.6 years in the Czech Republic and Italy to 2.6 years in the Netherlands). The findings showed that a quarter of the people with dementia had been diagnosed with another condition prior to dementia and that almost...
half of the carers (47%) felt that the diagnosis would have been better earlier (ranging from 36.5% in the Netherlands to 52.1% in Italy).

**Barriers to timely diagnosis**

Amongst the key identified barriers to receiving an earlier diagnosis, carers reported the first professional seen not considering that anything was wrong (33%), had not believed that it was worth pursuing a diagnosis (6.6%) or that the person with dementia had refused to seek help (37.9%).

Prof. Woods highlighted that there had been little change in relation to the time it had taken for people to get a diagnosis and that the proportion of people thinking that a diagnosis should have been made earlier did not differ according to whether the diagnosis had been made before or after 2013.

Another interesting finding of the project was the differences between countries with regard to whether the person with dementia had been informed about the diagnosis. Whilst this was the case in the overwhelming majority of cases in Finland (99%), the Netherlands (92%) and Scotland, UK (96%), the percentage was lower in the Czech Republic (77%), while in Italy, only a minority of people (41%) had been informed about their diagnosis.

**Post-diagnostic support in Europe**

Prof. Woods also presented the type of information carers had received after the diagnosis. The most frequent types of information related to drug treatments (56%), dementia itself (48%), disease progression (38%) and Alzheimer’s associations (38%). Carers reported that they would have liked to have received information on more practical coping strategies and living well with dementia (51%), as well as what services were available for them (46%).

On the whole, the list of services carers had been able to access in the 6 months after the diagnosis included information and advice on practical matters, medication and non-pharmacological treatment for the person with dementia, dementia support services (e.g., respite care, day services) and formal support networks and services (such as Alzheimer’s associations and counselling services).

**Olga Sehnalová, MEP (Czech Republic)**

“As a Member of the European Parliament and the European Alzheimer’s Alliance, I am interested in how European countries differ in their approach to dementia. Despite the growing recognition of dementia as a public health priority and the development of national dementia strategies, the Alzheimer Europe survey highlighted that barriers to timely diagnosis continue to exist. Although in the Czech Republic, the time to diagnosis is relatively short compared to other countries, we cannot consider it a success that it takes more than a year and half. I hope that EU initiatives such as the EU Joint Action on Dementia will identify good practice and make recommendations on how to improve timely diagnosis and post-diagnostic support across all European countries.”
In conclusion, Professor Woods highlighted the continuing obstacles to timely diagnosis, the country differences in the sharing of the diagnosis and the significant unmet needs in the provision of information and post-diagnostic services. He therefore recommended the continuation of awareness raising and education initiatives.

The role of the European Union in supporting carers

The next speaker at the lunch debate was Sarah Schinazi from the European Commission’s Directorate General for Employment, Social Affairs and Inclusion, who spoke about how the European Union can support carers. Specifically, she highlighted the importance of the European Pillar of Social Rights, which was jointly proclaimed by the European Parliament, the Council and the Commission on 17 November 2017 at the Gothenburg Social Summit for Fair Jobs and Growth.

The pillar provides 20 principles grouped under three main headings:

1. Equal opportunities and access to the labour market.
2. Fair working conditions.
3. Adequate and sustainable social protection.

Promoting work-life balance through the introduction of carers’ leave and flexible working arrangements

The content and ambition of the European Pillar of Social Rights build on a large number of Commission initiatives in the employment and social field. Sarah Schinazi singled out work-life balance and long-term care as being particularly relevant for the discussion on carers’ rights and support. The key objective of the work-life balance initiative is to address women’s underrepresentation in the labour market and to go beyond a simple revision of the maternity leave directive.

One of the proposals would therefore be to introduce a right to carers’ leave through a new European directive. The proposal would provide the right to carers’ leave of up to 5 days per year which would be compensated at the same level as sick pay, open for people caring for a dependent relative with a serious illness, serious medical condition or disability.

In addition, the proposal for a directive aims to introduce the right to request flexible working arrangements. This right would be open to parents of children up to the age of 12, but also to carers who can request reduced working hours, flexible working hours or flexibility on the place of work.

In its Communication, which supplements the proposed directive, the Commission also identified “improving access to care services” as one of the three policy areas which should be addressed. This would be done through a combination of tools to support Member States, such as a better collection of EU-level data, better monitoring guidance and benchmarking through the European Semester and the sharing of good practice in this field. Furthermore, it was indicated that funding through European programmes such as European Structural and Investment Funds (ESIF), the European Social Fund (ESF) and the European Commission’s Programme for Employment and Social Innovation (EaSI), could also support this work.

During the ensuing discussions, Nessa Childers MEP (Ireland) questioned how the European Union could support a greater
gender balance when it comes to people caring for older people as she was particularly struck by the fact that over 80% of the respondents of the carers’ survey had been women.

In her closing comments, Sirpa Pietikäinen MEP (Finland) highlighted some of the findings of the carers’ survey had identified and was satisfied that in Finland, people were informed and involved during the diagnostic process. However, the delays for a diagnosis remained too long, as with other countries. As a Member of the European Parliament, she also welcomed the initiative of the European Commission to promote a better work-life balance and hoped that Member States would support the right to carers’ leave proposed by the Commission.

Sirpa Pietikäinen, MEP (Finland) and Vice-Chairperson of the European Alzheimer’s Alliance

“I was delighted to see that people with dementia in Finland were systematically informed about their diagnosis and included in care planning decisions. Despite this, the delays before receiving a formal diagnosis on dementia remain significant. Across Europe, we need to continue to invest in awareness raising campaigns targeted at the general public, medical training of general practitioners and specialists, and address some of the system delays when it comes to referrals and access to diagnostic services.”

Nessa Childers, MEP (Ireland) raises impact of care on women
At Roche, we work with a purpose.

We discover and develop innovative medicines and diagnostic tests to help people live better, longer lives.
Alzheimer Europe Carers’ Survey highlights significant barriers to timely diagnosis

The highlights of Alzheimer Europe’s survey of carers’ experiences of dementia in five European countries were presented at the European Parliament lunch debate on 26 June (see previous article). Some of the policy implications of the findings are included in this article.

Diagnosis is crucial for people with dementia and their families and this premise served as the basis for the Alzheimer Europe survey, which received responses from 1,409 informal carers in five European countries (Czech Republic, Finland, Italy, Netherlands and Scotland, UK), sharing their experiences of the diagnostic process.

The overall conclusion of this study is that whilst some aspects related to diagnosis may be improving, we could not identify a clear change in the experience of receiving a diagnosis of dementia, over the last decade. In addition, it is evident that post-diagnostic support continues to be a major issue across Europe, with a number of key differences in the experience of diagnosis and post-diagnostic support in different countries.

The findings of the survey showed that the most common first indication of a problem (which prompted help-seeking) related to memory problems/confusion. This is the same finding that was reported in the carers’ survey conducted by Alzheimer Europe in 2006. Furthermore, as in 2006, the survey highlighted that difficulties with activities of daily living, difficulties with communication and issues related to mobility (e.g. travelling, driving) continued to be significant issues which were frequently experienced and acted as triggers for help-seeking. This is important as dementia is frequently portrayed as a memory condition: this should be taken into account when raising awareness about dementia and promoting timely diagnosis.

Delays to diagnosis remain considerable

According to the survey results, it took an average of 2.1 years to receive a diagnosis (from the point where the carer noticed a problem). This is almost the same figure that was reported in a similar study in 2005 ("Facing Dementia" study). No relevant differences in this timeframe were apparent in the most recent years (see figure 1).

Differences were also present between the countries surveyed (see table 1). The findings showed that it often takes a longer period of time for people to seek help after noticing the first symptoms. The Czech Republic seemed to perform particularly well in this area and several carers had a very short period of time between identifying a problem and assessments being carried out (including visiting specialist clinicians). Across all surveyed countries, general practitioners (GPs) continue to be the healthcare professionals from whom carers first seek help.

A significant change can be seen in where people receive their diagnosis. Whereas in 2006 as many people were diagnosed in hospital as by their GP, this no longer seems to be the case. Diagnoses are now more frequently made in a memory clinic or outpatient service of a hospital, with only a small proportion of people being diagnosed by GPs. Most carers reported that the person with dementia had undergone memory tests, interviews and brain scans. As would be expected, lumbar punctures were less common, however, these were slightly more frequent in the Netherlands. The number of people with dementia in the Czech Republic who had a brain scan was much lower than in any other country.

Misdiagnosis of other conditions prior to dementia diagnosis remains an issue

A significant number of carers reported that the person had been diagnosed with another condition prior to dementia, which reinforces...
what we have often heard from people with dementia and carers, who have told us about how distressing this can be. Depression was one of the most frequent conditions with which people with dementia were diagnosed prior to the diagnosis of dementia.

The majority of people had received a diagnosis within the five years prior to completing the survey. An important and positive finding is that two thirds had been diagnosed at early stages (mild dementia or Mild Cognitive Impairment) and only 4% had received the diagnosis at advanced stages. However, the majority of carers would have preferred an earlier diagnosis (see figure 2). This was more frequent as the severity of dementia increased.

**Huge differences exist across Europe with regard to the disclosure of diagnosis to the person with dementia**

One in five people with dementia were not informed about their diagnosis. However, considerable variation exists between the countries. In Italy, the majority of people with dementia had not been informed about their diagnosis (see figure 3) which directly went against the expressed wish of the person with dementia in all but a few cases.

A positive finding was that when diagnosis was disclosed, carers seemed to be quite satisfied about the way in which it had been done. Important aspects included the feeling that the doctor was well prepared, had explained everything clearly and had established a good relationship with the person with dementia.

We know that receiving a diagnosis can be a lifechanging experience and this was reflected by the majority of carers reporting that they were worried about the future. Many carers and people with dementia felt sad at the time of diagnosis, however, after some time, whilst many still had sad emotions, other more positive feelings such as acceptance also emerged. Overall, the negative emotions tended to be less prevalent after a period of time.

**Information at time of diagnosis is often lacking**

One of the main gaps identified in the 2006 survey was that many carers (19%) had not received any type of information at the time of diagnosis. This finding was identical in 2017, where 19% of the carers again reported that they had not received any information. In the case of people with dementia, this percentage was even higher (27.9%).

The majority received information on medical aspects and pharmacological treatment but information on psychosocial aspects was not often provided, with information about participation in research being the least commonly provided. The provision of information about available services was also relatively low overall. Despite this, almost every carer reported using different sources of information to keep up to date on dementia, especially from online sources. In addition, the findings showed that the role of Alzheimer associations in providing information was very important.

The survey has highlighted several unmet needs in the area of provision of information and access to services and supports. The need for information on coping and living well with dementia, as well as the available services was demonstrably high. In particular, many carers reported not having access to an assessment of their own needs, a care plan for the person with dementia or access to counselling services, but would have liked to have used all of these services.

The majority of the carers shared the diagnosis with other people, though this tended to be with close family and less so with close friends. Importantly, many carers felt that the person with dementia was still valued and respected by other people, particularly within their own families. Fewer people had shared the diagnosis with other people in their communities and often felt that after the diagnosis, the person with dementia was no longer able to carry on with community activities and roles. Furthermore, loneliness as a consequence of their role as a carer was frequently reported.

**Unmet needs identified in the AE survey**

In conclusion, findings from the survey present a range of positive and negative experiences of carers. Whilst the time to receive a diagnosis has not substantially changed in
the last decade, it appears more people are being diagnosed by specialist services, with many places now using technology such as brain scans as part of the diagnostic process.

The findings highlighted the important differences in the experience of diagnosis based on the country where a person lives, with Italy and the Czech Republic having the shortest times for diagnosis and people with dementia in Italy having good access to diagnostic tests.

More people than in 2006 were informed of their diagnosis and it appears that doing so is common practice in most countries. Finland, the Netherlands and the UK (Scotland) were particularly good at disclosing the diagnosis to people with dementia and, in general, carers seemed more open to sharing the diagnosis with other members of the community. However, the finding that in Italy, the majority of people who were diagnosed were not informed of their condition is perhaps evidence of significant cultural differences between countries.

There is a clear need across all countries for better involvement of people with dementia in the full diagnostic process. We believe that every person with dementia should be given the opportunity to decide whether or not he/she wants to know the diagnosis and who should be part of the process.

Furthermore, there is an identified need for more work in relation to post-diagnostic support to ensure that information and support on relevant aspects such as advance care planning, legal rights, driving and, in particular, opportunities to take part in research, is better incorporated into the diagnostic process, for both people with dementia and their carers.

Too many carers still have unmet needs with regard to information and support during the diagnostic process and thereafter. The associated emotions (including sadness and loneliness) must also be addressed. Whilst positive changes are already evident in many communities, further work must continue around awareness raising and to ensure communities are more inclusive for people with dementia and their carers.

Figure 3: Diagnosis shared with person with dementia by country (n=1400)

Acknowledgements

Alzheimer Europe would like to thank the carers from the five countries who participated in this survey and made this research possible. We are indebted to Professor Bob Woods from Bangor University for his leadership in this project and to our colleagues from the five participating Alzheimer’s associations for their contributions. We also gratefully acknowledge the educational grant provided by Roche, which allowed Alzheimer Europe to carry out and analyse this survey.
Developing intercultural dementia care and support for people from minority ethnic groups in Europe

Dianne Gove, Alzheimer Europe’s Director for Projects gives an overview of the organisation’s current work on dementia and minority ethnic groups.

In keeping with ongoing efforts to promote the rights and wellbeing of people with dementia, Alzheimer Europe is currently working on a project to improve intercultural care and support for people with dementia and informal and professional carers from minority ethnic groups. This work is funded through an operating grant of the health programme of the European Commission and an educational grant of the Robert Bosch Stiftung.

Dementia can be disabling, preventing people from participating in society on an equal basis with others. As emphasised in last year’s work on disability and dementia, according to the social and rights-based models of disability, barriers to equal participation in society do not reside solely in the individual but are also the result of the way that society is organised (including attitudes, practices, physical structures and procedures).

Reasonable accommodations must be made to maximise the potential of people with disabilities (including dementia) to participate in society on an equal basis with others. However, when determining what is “reasonable”, there is a risk of this being based on the needs and wishes of the main ethnic group and not on those of people with dementia from minority ethnic groups.

Intercultural care and support is not merely about services that are adapted to the needs and wishes of people from different ethnic groups but also closely linked to people understanding and respecting cultural and linguistic diversity. This means ensuring that people from all ethnic groups are aware of dementia, know where to get information, benefit from accurate and timely diagnosis and receive appropriate and good quality care and support. This does not always happen. People from minority ethnic groups often lack knowledge about dementia and available services, are frequently misdiagnosed and typically have a low uptake of dementia services.

An expert working group has been set up to promote the development of intercultural care and support across Europe, for which Alzheimer Europe liaised with representatives of its national member organisations and its European Working Group of People with Dementia to identify ongoing initiatives, projects and good practices.

Members of the expert group (see text box for all names) have extensive expertise and experience in intercultural dementia service development and identified a number of key issues for further exploration. These include, amongst others, the need for culture-sensitive assessment and diagnostic tools, an understanding of how different perceptions of dementia affect help seeking, filial piety, gendered care roles, lack of trust in health and social care providers, experiences of stereotyping and prejudice, stigma, language difficulties and issues of relevance to migrant and live-in carers.

Stereotypes and assumptions (e.g. people from minority ethnic groups “look after their own” and don’t want any support) are still common but things are gradually changing. The expert working group will produce a report, recommendations (targeted mainly at policy makers and service providers) and a database of good practices. These should be available at the end of 2018. The report will be translated into French and German at the beginning of 2019.

Expert group members

Dianne Gove, Alzheimer Europe, Luxembourg (Chair)
Jean Georges, Alzheimer Europe, Luxembourg
Daphna Golan Shemesh, Alzheimer Association of Israel
Michal Herz, University of Worcester, United Kingdom
Siiri Jaakson, ETNIMU project, Finland
Ripaljeet Kaur, BME Dementia Service, Touchstone, United Kingdom
Debi Lahav, Alzheimer Association of Israel
Sahdia Parveen, University of Bradford, United Kingdom
Charlotte Plejert, Linköping University, Sweden
Mohammed Akhlak Rauf, Meri Yaoadaln Dementia, United Kingdom
Thomas Rune Nielsen, Rigshospitalet Copenhagen, Denmark
Carolien Smits, Windesheim University, Netherlands
**PARADIGM: Improving the engagement of patients in the process of developing medicines**

Alzheimer Europe reports on its involvement in and expectations from the PARADIGM (Patients Active in Research and Dialogues for an Improved Generation of Medicines) project.

There is a growing interest in and consensus on the relevance of engaging patients throughout the lifecycle of medicines development. On the one hand, patients’ views, expectations and experiences are crucial as they are living with the medical condition, experiencing the symptoms and will be the people taking the medicines as part of their treatment. On the other hand, there is increasing evidence that patients’ input and collaboration can also bring important benefits for those developing the medicines or involved in this process. Despite this, patients continue to be a largely underutilised resource in medicines development.

While there are many initiatives emerging to involve and engage with patients, inconsistency and fragmentation remain the norm.

With this in mind, the PARADIGM project was launched on 1 March 2018 with the ambitious aim of making meaningful patient engagement in the development of medicines a reality. Within the medicines lifecycle, the project focuses on patient engagement at three key decision-making points: 1. research priority setting, 2. design of clinical trials and 3. early dialogues with regulators and health technology assessment (HTA) bodies.

**Patient engagement tools and metrics**

The project will develop a framework that will enable structured, effective and sustainable patient engagement. This will include:

- A set of comprehensive tools and practices for implementing patient engagement
- Agreed metrics to measure the return on engagement from the perspectives of different stakeholders.

PARADIGM will run for 30 months, thanks to funding received from the Innovative Medicines Initiative 2 Joint Undertaking. The consortium is led by the European Patients’ Forum (EPF) and the European Federation of Pharmaceutical Industries and Associations (EFPIA) and comprises a mix of partners including patient organisations, regulatory bodies, universities, non-profit organisations, SMEs and trade associations to pharmaceutical companies. Four European patient organisations and one research foundation are actively involved in this project:

- Alzheimer Europe (AE)
- European AIDS Treatment Group (EATG)
- European Organisation for Rare Diseases (EURORDIS)
- European Patients Forum (EPF)
- Sant Joan de Déu Research Foundation (SJD)

Mathieu Boudes, PARADIGM Project Coordinator, European Patients’ Forum

“The mission of PARADIGM is to participate in the co-creation of a sustainable framework to allow meaningful, ethical, systematic patient engagement in medicines R&D. This work is done in close collaboration with other kindred initiatives and is in line with the overall strategy of IMI. The 34 partners of our consortium think alike, are aligned on goals and committed to making patient engagement better in the near future.”
will ultimately inform the development of the framework that will be co-created by the consortium partners.

To achieve this, several instruments will be used including the review of the literature, an online survey, a Delphi study and face-to-face consultations. The online survey has already been completed by over 500 participants. To gain a better understanding of the needs of people living with dementia and young people, face-to-face consultations are also being conducted.

The first of these consultations took place during the meeting of Alzheimer Europe’s European Working Group of People with Dementia (EWGPWD) in Brussels on 27 and 28 June 2018. The consultation was co-facilitated by Alzheimer Europe (Ana Díaz, Dianne Gove), Sebastien Libert (PhD student, INDUCT) and representatives from industry (Sharareh Hosseinzadeh, Novartis), academia (Suzanne Ii, University of Oxford) and HTA bodies (Neil Bertelsen, HTAi).

### About PARADIGM

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### Madga Chlebus, Executive Director of Science Policy & Regulatory Affairs at EFPIA (European Federation of Pharmaceutical Associations)

“Patient engagement becoming a reality and a standard practice will have a genuinely ground-breaking effect on biomedical research, as it will make it more focused on people’s needs. The public private Innovative Medicines Initiative, with its aim to modernise medical research, is a perfect platform for this objective and the perfect springboard for PARADIGM.”

### Sharareh Hosseinzadeh, Global Head Clinical Patient Engagement, Novartis

“By partnering with our patients, we understand the unmet needs and are more able to integrate patient insights into the design of studies. The IMI PARADIGM consultation has been very useful, as it provided an opportunity to listen to each other and understand diverse expectations. It was particularly helpful to understand the needs of people living with dementia and their friends/families. Big thanks to the EWGPWD and all the participants for their openness to this partnership.”

### Suzanne Ii, Postdoctoral researcher, University of Oxford

“I had a memorable experience speaking to people with dementia through our IMI PARADIGM consultation. The two days we spent with everyone provided an opportunity to communicate in a way that enabled everyone to share their personal experiences and their specialist knowledge. I hope this consultation serves as one example of how we can better engage with patients and carers to understand how to improve patient engagement overall.”
In the interview below, Chris Roberts, Vice-Chair of the European Working Group of People with Dementia (EWGPWD) and his wife Jayne Goodrick, discuss their experiences of taking part in this consultation.

Chris and Jayne live in North Wales (United Kingdom). Chris was diagnosed with early onset mixed dementia (vascular and Alzheimer’s) in 2012, in his early 50s. Since the diagnosis, Chris and Jayne have been actively involved in raising awareness of dementia and have inspired many other people to continue to live life to the full with dementia.

Chris, can you tell us a bit about your personal experience of patient engagement?

Chris: I have been lucky to be engaged in quite a few projects over the last couple of years, especially since I joined the EWGPWD. This involvement gives people value, a purpose, which sadly after a diagnosis you usually lose. It also stimulates the brain and senses, gives you extra exercise, which are so important for those affected by dementia.

How do you feel about the idea of patient engagement in the process of developing medicines? Do you think this is relevant for people with dementia?

Chris: As you can imagine, it would be very important for people with dementia to find ideally a cure, but also better and improved treatments for all different types of dementia. This has to be done in collaboration with us, with the people affected by dementia, so patient engagement in this area is not just important, it is fundamental. Patient engagement and involvement can save money and time, give valuable insight and advice that you can only receive from someone living with the condition. I am living with my illness daily. I experience and feel things that can’t always be learnt by the professionals in my care or sat around a committee table. We just need support, understanding and reasonable adjustments to be made, we need to be asked what we require to participate. Some people may have already got a relevant background or education to be able to understand the process. Others may need training, information or some kind of preparation.

Jayne: To answer your question about patient engagement and whether this is relevant for people with dementia, I would pose the question: Why wouldn’t it be relevant for people with dementia? If this is relevant to other disease areas, why wouldn’t it be relevant in the dementia area? The key issue should be supporting the person in any way that may be needed, making sure that the person feels confident about participating in the discussions.

You recently participated in a consultation for the PARADIGM project as part of the EWGPWD. How did you feel about taking part in this consultation as an expert by experience?

Chris: This at first seemed a bit daunting, but with the information and background that was given and discussed, it ended up being a very interesting day. I felt that everyone in the room learnt new things and enjoyed the experience of the day. It was great to have three representatives from PARADIGM in the meeting. They were very patient, down to earth, very open and they did not mind explaining things, which is excellent. I would like to thank them on behalf of the group for being so generous and sharing their time, knowledge and experience with us.

Chris: In the consultation, we discussed many of the details and practicalities that should be taken into account before, during and after the patient engagement activity. But a key message which, I think, is particularly important is that involvement should never be a ticking the box thing. If you want to do this engagement process, don’t just tick a box, get suitable candidates, spend a bit more time and resources. Patient engagement should be a positive experience and should be beneficial for all involved: patients, supporters and the people organising the engagement activity. Also, it is important for us to have feedback about how our contribution was used and how we can make our contributions better in the future. We want to do our best but if they don’t tell us, we don’t know.

Jayne: From the perspective of the person supporting the person with dementia, I think it is important to be clear what the expectations are. One of the difficulties I often have in the various places we go to is that I am the supporter and I am not sure if I am there as supporter to support Chris or I am there to contribute in my own right. I am never sure whether I have permission to speak, if you like. Also, if the person has never participated in something like this, some briefing or training may be important.

Was there anything that you found particularly interesting about PARADIGM?

Chris: I found everything very interesting. A lot of what was discussed I had never considered or known about. It was good to take part, learn and share. I particularly liked that PARADIGM is working towards making patient engagement possible for ALL patients. Respect, inclusion and diversity seemed to be quite important for this project. We, as people affected by dementia, do really appreciate the lengths that these organising agencies and companies go to in order to involve us, and we absolutely appreciate what they are trying to do on our behalf.

Jayne: As Chris has said, it was absolutely great to have three people from the project and in particular three people with such a wealth of experience and who were so passionate about patient engagement. I appreciated the respect given to the group. What I enjoyed the most about the consultation was the interaction, the cross learning. Personally, I loved the back-and-forth interaction. It was two way: they learnt from us and we learnt from them.
The EPAD project reports on significant progress in 2018

Global efforts and cooperation between participating researchers are at a point of coming to fruition with new knowledge generated and innovative compounds about to be tested with the cumulative goal of advancing research in Alzheimer’s disease and preventing dementia.

The European Prevention of Alzheimer’s Dementia (EPAD) project officially started on January 2015 for a duration of five years. The EPAD project is an interdisciplinary research initiative across Europe to better understand early aspects of Alzheimer’s disease and to prevent dementia before symptoms occur. It combines knowledge and expertise from 38 European organisations from academia and industry, bringing together a wealth of experience to its activities and making it the largest ever public-private partnership in Alzheimer’s disease research.

EPAD research participants at the heart of the EPAD project

EPAD has created the first single, pan-European register of over half a million people across the risk spectrum for dementia. From this register, research participants are invited to join an EPAD cohort of potentially at-risk subjects: the EPAD Longitudinal Cohort Study (LCS). At the end of August 2018, the EPAD project had a total of 907 enrolled research participants in the LCS across 20 European active centres. Besides seeing that each site is improving recruitment and more than doubling the monthly recruitment rate, the EPAD family of trial delivery centres grew in 2018 with 10 new sites joining. Additional sites are expected to become operational, with the aim of having 30 sites open and recruiting before the beginning of 2019, with more planned to come on board in the following months.

In addition, two EPAD research participant panels have been established in Barcelona and Edinburgh which involve research participants in the study, giving them an active voice in the project and helping the collaborators to learn from their experiences.

Launch of the proof-of-concept platform

EPAD has developed a proof-of-concept (PoC) platform in which new compounds can be tested in a streamlined way, delivering more effective, targeted interventions that can slow or stop dementia. The EPAD PoC platform is now ready to receive interventions for testing in a secondary prevention population. It has been designed to accommodate pharmacological and biological interventions that
are Phase 2 ready, offering pharmaceutical and biotechnology organisations as well as academic institutions and partnerships an adaptive PoC trial designed to deliver early and accurate results in the most efficient way. The inclusion of the first candidate to take part in the PoC will likely happen in the first quarter of 2019.

EPAD researchers present at international conferences

The EPAD project has been very well represented at scientific and general conferences in the past several months. The most recent public facing activity of the project came at the Alzheimer’s Association International Conference (AAIC) which took place in Chicago in July this year. EPAD had a large booth in the exhibition area and a satellite symposium was organised to showcase the EPAD PoC trial which attracted companies and investors keen to understand more about EPAD and the benefits of using the platform for drug development. The organisation of this event came at a time where there was strong interest from a handful of companies. The interest in EPAD has noticeably increased in recent months and the launch of the PoC platform in Chicago will further accelerate these efforts.

EPAD will also have a presence at both the Alzheimer Europe and Clinical Trials on Alzheimer’s Disease (CTAD) conferences which will be held this year in October in Barcelona. The EPAD co-coordinator Professor Craig Ritchie (UEDIN) will deliver the closing session at the CTAD conference, where he will release the first data set (EPAD V500.0) from the EPAD cohort study and the predictors of amyloid status.

Development of new communication and branding tools

Alzheimer Europe is a full partner in this consortium and a co-leader of the “Dissemination” work package, which has developed communication and branding tools to increase the visibility of the project and to more efficiently reach a wider audience.

High quality content, in the form of a brochure explaining the PoC platform has been developed with the aim of generating interest from biotechnology companies by highlighting the EPAD adaptive strategy in this project compared to the usual trial practice. Furthermore, a new updated EPAD website has recently been launched. The website is devoted to informing different audiences about the project’s existence, its progress and achievements, including the scientific community, companies, people with dementia, their families and carers, as well as the general public.

The purpose of the update of the website is not only to improve its readability and user navigation but also to include two new landing pages for research participants and pharmaceutical investigators who may be interested in using the EPAD platform to test their compounds.

A successful General Assembly meeting in Amsterdam

This year, the EPAD project enjoyed a successful General Assembly from 23 to 25 May in Amsterdam under the banner “How to assure sustainability”. The meeting provided a chance to gather over 180 people from across many different countries who work on the EPAD project to discuss progress and future activities.

One of the highlights of this year’s General Assembly was the “Early Career Researchers” session. More than 50 young investigators involved in EPAD became fellows of the EPAD Academy over the last year. These young researchers showcased the work they are involved in and discussed ways of collaborating between meetings.

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.

About EPAD

EPAD is an Innovative Medicines Initiative (IMI) project aiming to improve the understanding of the early stages of Alzheimer’s disease and deliver new preventative treatments.

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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.

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Providing European leadership in research and innovation

As Horizon Europe, the new European research programme is being developed, Alzheimer Europe talks to Carlos Moedas, EU Commissioner for Research, Science and Innovation about current and future European priorities for dementia research.

The new research programme is one of the few EU budgets to go up in the Commission’s seven-year proposal. What will the priorities be for the next seven years?

The top priority is to help Europe become the global innovation powerhouse that it has the potential to be. We are a global leader in top-class research, but we can do better in translating these results into innovation that boosts economic growth and creates jobs. There is no doubt that research and innovation are crucial for Europe’s future prosperity.

The proposal for Horizon Europe, our research programme for 2021–2027, is built on that principle. Indeed, the proposed budget, nearly EUR 100 billion, clearly shows our commitment to European leadership in research and innovation. This increase amounts to as much as 50% when taking into account the EU of 27 Member States.

The new programme builds on the achievements of Horizon 2020, our current programme, which is a European success story. So we keep the same basic structure and little will change in terms of rules and procedures for participation. We also introduce some important new elements that have a common aim to increase the impact of EU research and innovation funding.

One of them is the establishment of a European Innovation Council, a flagship initiative in Europe to identify high-risk, fast moving innovations that can create entirely new markets. Another is launching EU-wide research and innovation missions with bold, ambitious goals and strong European added value.

We are delivering on this top priority for the EU, and equipping ourselves to thrive in the society of tomorrow. Horizon Europe will make a real difference in the lives of citizens and society as a whole.

Looking back at the current Horizon 2020 research programme, what have been the key achievements in the dementia field?

Since the beginning of Horizon 2020 in 2014, the Commission has invested some €462 million in 258 dementia research projects covering the entire spectrum of the disease. The main drivers of the research are personalised medicine, digitalisation of healthcare and implementation research.

Carlos Moedas, EU Commissioner for Research, Science and Innovation
Under the Innovative Medicines Initiative 2 (IMI2), the EU's public-private partnership with the pharmaceutical industry, the project PHAGO shed some light on the role of neuro-inflammation in Alzheimer’s disease to pave the way for future development of personalised therapies. Another IMI project, EPAD, made tangible progress in identifying the early stages of the disease. EPAD together with IMI’s EMIF-AD and AETIONOMY forms the IMI Alzheimer’s disease platform, which has a combined budget of €138 million.

Personalised medicine has also been addressed through the EU Joint Programme for Neurodegenerative Diseases Research, which has invested €150 million in nine transnational calls for proposals and funded projects such as BRIDGET, which addresses late diagnosis in Alzheimer’s.

Data is a key enabler for the digital transformation of healthcare services, and Horizon 2020 projects such as EUROPOND are developing computational models that can identify characteristic patterns of progression for some brain diseases, including Alzheimer’s.

The EU is also part of the Global Alliance for Chronic Diseases (GACD), a collaboration between 14 funding agencies for ensuring that known, effective health interventions are implemented in real settings, globally. Mental disorders were the focus of a topic in 2017, from which two projects on neurodegenerative diseases emerged: PRODEMOS (for promoting self-management of risk factors in dementia patients) and RECAGE (develops specialised care units to better manage symptoms in dementia patients).

We also launched an initiative on “Coordinating European brain research and developing global initiatives” to promote coordination among European researchers.

There is a new idea for “Research Missions” and dementia has been mentioned as a topic for one of these missions. How would this work in practice?

It is too early to go into detail about the missions because they have yet to be designed. But what I can say is that they will be co-designed by stakeholders and citizens. This could be done as part of mission boards that will be set up after a public call for expressions of interest.

The idea behind the missions is to set out an easy-to-understand (and easy-to-measure) goal that is to be achieved within a specified timeframe. The missions, crucially, must be able to generate bottom-up solutions, and will consist of a whole portfolio of different cross-cutting actions.

Examples of potential missions could be: “Forgetting Alzheimer’s”, “Plastic-free oceans”, or “Women on Mars”. These kinds of goals are not only easy to comprehend, but they capture the imagination of regular citizens. They also make it easier to conclude if the mission has been a success or not. The missions are intended to help solve some of society’s most pressing problems, and there will be a public call for feedback in order to determine which issues we need to target. Relevant stakeholders will be consulted when a mission is designed in their area of work.

In terms of next steps, the first missions will be introduced in the first work programme of Horizon Europe, which will launch in 2020. After two years we will take stock and decide if the number and scale of the missions need to be adapted.

Potential missions could be: […] “Forgetting Alzheimer’s”. These kinds of goals are not only easy to comprehend, but they capture the imagination of regular citizens.”
The EU Joint Action on dementia: Collaborating among European countries to improve the lives of people with dementia and their carers

Act on Dementia is an EU Joint Action (Grant Agreement No. 678481) which began in March 2016, and has received funding from the European Union’s Health Programme (2014–2020). Its aim is to promote collaborative actions among Member States to improve the lives of people with dementia and their carers.

The provision and quality of services for people living with dementia and their carers have improved but they are not consistent across European Members States. This was the rationale for the launch of Act on Dementia, a 3 year EU Joint Action which began in March 2016.

The aim of the Act on Dementia joint Action is to promote collaborative actions among Member States to improve the lives of people with dementia and their carers. It will provide practical guidance for policymakers developing and implementing their national dementia plans, policies and strategies. It aims to provide cost-effective and practical examples of the core components of good dementia diagnosis, care and support.

Partners working together on this Joint Action (JA), which is being coordinated by the Scottish Government, are from Bulgaria, France, Greece, Italy, the Netherlands, Norway, Poland, Romania, Spain and the United Kingdom.

The four key areas of focus for Act on Dementia have been: diagnosis and post-diagnostic support, crisis and care coordination, quality of residential care, and dementia friendly communities. Evidence reviews have been completed during the first phase of the JA (2016–2018) and can be found under the resources section of the Joint Action’s website at www.actondementia.eu.

Diagnosis and post-diagnostic support

This work aims to provide evidence based approaches which have been tested in practice, to support improvements in diagnosis and post diagnostic support across EU member states.

The rate of dementia diagnosis varies greatly between Members States and in many places post-diagnostic support is non-existent, or at least underdeveloped. Where a diagnosis occurs later, or is poorly communicated, and unsupported by subsequent interventions, the risk of institutionalisation and other poor outcomes is significant for the person with dementia and their carer/family. This is not optimal for the person with dementia, their carers or the health and social care system in which they live.

Improving diagnosis rates and post-diagnostic supports for people with dementia and their carers allows people with dementia, their families and those involved in their care to benefit from timely access to treatments, interventions, information and education, as well as services which can improve the quality of life, facilitate hope and the opportunity to live well with dementia for as long as possible. Better care planning, facilitated by post-diagnostic support can also contribute to reducing health and social care expenditure on preventable hospital and residential care admissions for people with dementia. And importantly to support people to make decisions about their future whilst they still have capacity to do so.

This work has been led by Professor Pierre Krolak-Salmon who is a neurologist and geriatrician at the University Hospital of Lyon (France) and the director of the Clinical Research Memory Centre of Lyon and the Clinical Research Centre “Elderly, Brain and Frailty”.

Work is now under way to implement pilot projects which include:

- A de-stigmatisation programme for GPs is taking place in Bulgaria, France and Poland asking GPs to consider dementia as a real disease; the project is running training sessions in Limoges, Lyons, Lublin and Sofia (with 85 particularly newly qualified GPs). Questionnaires will be sent before and after the training about stigma, stereotypes and knowledge about diagnosis pathways.
- Pilot testing of GP/nurse cooperation programme is taking place in Bulgaria, France and Italy. So far 5 nurses in France and 20 in Bulgaria have been instructed with a

Joint actions are a financial mechanism in the Health Programme to cover specific health-policy needs. They support EU cooperation with an important number of partners which are either competent health authorities in the Member States or other organisations designated by these competent authorities. Joint actions generate momentum for wider impact. The gains for the Member States involved can be substantial in terms of knowledge and experience exchanged.
Further 29 being targeted in Modena, Italy. One of the challenges has been to secure GP agreement.

- Pilot testing of tele-medicine in care homes is being conducted in Bulgaria, France and Greece. Real challenges have arisen due to data protection legislation, but 7 nursing homes are participating using 4 common detection scales.

### Crisis and Care Coordination

People with dementia need different sorts of care and their need for care can increase as the disease progresses. In most health and care systems dementia care will be provided by a range of different organisations, each working under different eligibility and funding rules and often without clear co-ordination. As an outcome, the experience can feel fragmented.

People who are confused due to their dementia, get confused even more by the different care providers, and their different systems and points of contact and their carers often have to take on responsibility for care co-ordination themselves.

It is also important that physical environments are adapted to help enable people to live as well and safely at home as possible for as long as they can. In situations of crisis, where the person with dementia, or their primary carer has an acute episode of illness or trauma, the person with dementia may be admitted to hospital or a residential care institution. Admission to institutional care is often unnecessary and is a result of either limited access to alternative and more appropriate care, or lack of care co-ordination between health and care providers.

Family care-givers often report significantly increased anxiety, apathy, resistance to care, and distress in these types of crisis situations. Care navigation models, crisis support models and better practice can significantly reduce strain on care-delivery systems by incorporating non-pharmacological interventions, assisting families with communication, and reducing family distress during symptom crises.

This work is jointly led by Italy and the Netherlands. Professor Nicola Vanacore is a senior neuro-epidemiologist at the Italian National Institute of Health (INIH) and is the Head of the Promotion and evaluation prevention policy of chronic diseases Unit at the National Centre for Disease Prevention and Promotion Disease. Jacqueline Hoogendam who co-leads the work package, is a senior policy advisor at the Ministry of Health, Welfare and Sport of the Netherlands and works on International Dementia issues.

Next steps for this work involve pilot sites which are engaged in training GPs and care managers (face to face and by online learning modules) to identify and deal with the signs of stress and distress in patients with dementia. Care co-ordination approaches are being tested in some test site areas to support people before, during and after a diagnosis of dementia, for example through group sessions and one-to-one support.

### Residential Care

As dementia progresses, many people in the later stages will require round the clock care, and depending on family and environmental circumstances this may lead to admission to a residential care establishment. A large proportion of nursing and residential care home residents have dementia (in some countries up to 80%).

It is important to ensure high quality professional care, including palliative care, is delivered with dignity and compassion within residential and nursing care establishments. A specific issue for people with dementia in residential care is the overuse of antipsychotic medication to manage stress and distress behaviours. It is important that people with dementia in these settings are prescribed such medication only as a last resort, that there is a range of alternative psychosocial interventions including therapeutic activity and interventions available and that when medication is used, its use is reviewed regularly.

This work is led by Øyvind Kirkevold, Nurse and Assistant Research Director at the Norwegian National Advisory Unit on Ageing and Health. The next phase of work includes:

- Pilot testing 6 projects (one on end-of-life care and five on behavioural and psychological symptoms in dementia [BPSD])
- Staff training
- Improving treatment of stress and distress and improving care in the last days of life

### Dementia-friendly Communities

Dementia-friendly communities can help to support people with dementia to live more independent and fulfilling lives in their own communities. Evidence has shown that appropriate support in the community can reduce the number of people with dementia being admitted to hospital and can delay their entry into care homes. As more Member States look at the costs of caring for people with dementia, there is an opportunity to develop alternative community support, to empower people with dementia to actively participate in society and remain independent for as long as possible – reducing stigma, isolation and fear by increasing community awareness and understanding.

Dementia in Europe 21

[Act on Dementia website (www.actondementia.eu)]
The UK Alzheimer’s Society conducted a survey via YouGov that found that less than half of the respondents to the survey thought their area was geared up to help them live well with dementia (42%) and less than half considered themselves a part of the community (47%). Stigma was particularly highlighted by people with dementia and carers. More than half of those surveyed thought that the inclusion of people with dementia in the community was fairly bad or very bad (59%).

Work has been undertaken to collate and provide evidence-based information and recommendations on promoting, nurturing and sustaining dementia-friendly communities. For example, defining what “good” looks like for a system-wide approach, understanding how good practice is sustained and promoting the various benefits, including economic benefits, for communities of being dementia friendly.

David Nuttall, the Deputy Director of Dementia and Disabilities at the UK Department of Health and Social Care, leads the dementia-friendly communities work.

Next steps include:

- Pilot testing in a variety of sites – a mix of large/small, urban/rural, different cultures, economies and health and social care systems and of fledgling and mature dementia-friendly communities;
- A core element of the testing is that people with dementia and families and caregivers will receive a survey before during and after testing; measuring inclusivity, isolation, stigma etc. and how easy it is to live their daily lives with dementia, including access to travel, shopping, banking, leisure and cultural activity.
- Work is also going on to consider harder indicators to measure the success of these pilots – e.g. hospital and home admissions and diagnosis.
- The initial activities in Bulgaria and Greece focus on “caregiver schools” – holding programmes in civic setting (a school) over 4 weekly meetings by healthcare professionals plus caregivers; sharing lived experience and opportunities for getting advice/having time-out. These are due to finish soon. Surveys are being conducted before and after. Anti-stigma leaflets are being prepared for schools, police, banks etc. raise awareness and increase access. Stigma questionnaires will be issued. Intergenerational activity will include children playing with elderly in a community setting; improving accessibility of local services through workshops with pharmacies, banks, public transport – taxis, buses, trains.

There are also three horizontal work packages which cut across the activities of the rest of the JA:

- Evaluation led by Maria-Dolors Estrada from AQuAS, Agency for Health Quality and Assessment of Catalonia;
- Dissemination led by Gillian Barclay, Scottish Government;
- and Coordination, led by Geoff Huggins, Director of NES Digital Service and Director of Health and Social Care Integration, Scottish Government.

Alzheimer Europe is a collaborating stakeholder of the Joint Action. This helps to ensure that the voices of people with dementia and their carers are central to the work.

Alzheimer Europe is a collaborating stakeholder of the Joint Action. This helps to ensure that the voices of people with dementia and their carers are central to the work. The organisation is represented by its Executive Director, Jean Georges who sits on the Joint Action Programme Board, and the European Working Group of People with Dementia has offered advice on different aspects of the work so far.

The work of the Joint Action will be showcased widely at the Alzheimer Europe Conference in Barcelona in October 2018. We look forward to seeing you there and will be happy to discuss our work further then. We hope to hold our final conference towards the end of 2019 when we will bring together and share the lessons learned.
Alzheimer Europe caught up with Gillian Barclay from the Scottish Government to discuss her experiences, challenges and hopes from her involvement in the coordination and dissemination work packages.

**What have been the biggest challenges so far in coordinating this joint action?**

I would have to say that the vote for Brexit in the UK just three months after the start of the JA was unexpected. It has made it a very important aspect of our work to reassure colleagues in the EU and our partners in the JA of our commitment to see this work through. Whatever our position in relation to Europe after 2019, there are still around 90,000 people living with dementia in Scotland, and an estimated 50 million worldwide. The aim of the JA is to promote actions to improve their lives and those of their carers and this work remains a clear priority for the Scottish Government.

It is also true that there are significant differences across our partner countries in how we approach caring for and supporting people with dementia. In some countries for example, the term “dementia” is not recognised. It has been important to try to understand these differences.

**What do you hope will be the most significant impact of the JA?**

If we can provide examples of excellent practice which can be adapted to suit different circumstances to decision makers in Member States (and wider) and provide tools to help other countries to implement these, then we will make a difference. In the timescale available (3–4 years), it is a challenge to demonstrate tangible successes, but that is what we are all working towards.

**What have you enjoyed most in the project?**

For me, it has been building relationships with the work package leaders and experts from other countries. It is a relatively rare opportunity for us as civil servants to work so closely with other nationalities, and one which I have enjoyed immensely. The role played by Alzheimer Europe in the project, and the contribution of the European Working Group of People with Dementia means that we maintain our focus on the people for whom this project will make the greatest difference and working with them has been a privilege."

*Gillian Barclay*

**The contribution of the European Working Group of People with Dementia means that we maintain our focus on the people for whom this project will make the greatest difference and working with them has been a privilege.**

*Gillian Barclay*
Sweden announces decision to launch national dementia strategy

On 24 May 2018 in Stockholm, Lena Hallengren, Swedish Minister for Children, the Elderly and Gender Equality, announced the Swedish Government’s decision to launch a National Dementia Strategy for Sweden. Our colleague Karin Westerlund from Alzheimer Sverige had the opportunity to catch up with the Minister about some of her thoughts on dementia during the summer campaign before the national elections on 9 September.

The National Dementia Strategy was announced with the overall ambition of equality in care for people with dementia. A first outline of the work-plan is to be presented to the Swedish Government on 10 October 2018 by the Swedish National Board of Health and Welfare. Following feedback from the Government, the Board will then present a revised work-plan which will be produced for the Swedish Government by 1 June 2022 and which will include long-term strategic issues, how to follow-up on them and key performance indicators for dementia in Sweden.

In May 2018 you announced a dementia strategy for Sweden. What do you hope will be achieved with the new strategy and how will it be developed?

It is estimated that 150,000 people are living with dementia in Sweden. The Swedish Government expects this figure to increase by over 50% by 2050. The number of individuals aged over 80 years is also expected to increase substantially, accounting for 15% of the total population, or a million people, by 2030.

It is of importance that all citizens get equal care, therefore equality of care is the cornerstone of the forthcoming Swedish Dementia Strategy.

Swedish citizens shall be able to expect that ageing is something secure. To meet these needs, the Swedish Government believes in organising health and welfare to a high standard, including assisted-care housing facilities in place in all Swedish communities, of which Sweden has 290, with qualified/skilled staff. All staff should be trained about dementia symptoms and the progression of neurodegenerative diseases.

Olivia Wigzell, the Director-General of the Swedish National Board of Health and Welfare has overseen the revision of the current Swedish National Guidelines for Dementia. This considerable task has been ongoing since 2010, with the Board working with the World Health Organisation as part of this work.

In October this year, the Swedish Government expects to receive a strong first plan for a Swedish Dementia Strategy, incorporating these key areas, from the Swedish National Board of Health and Welfare under the direction of Olivia Wigzell.

Then, work on the dementia strategy will commence, including working with the Swedish communities which have responsibility for the cost of nursing homes. In 2022 the plan will then be finalized and we wish to ensure that the plan is for the long-term with “future-proof” content.

Equality of care is the cornerstone of the forthcoming Swedish Dementia Strategy”

The proposed Swedish National Dementia Strategy consists of a number key areas:

- Cooperation between health and social care services.
- Staff-quality and competence building.
- Evaluation and follow ups.
- Caregivers.
- Civil society.
- Digitalisation and technical solutions as part of the care process for people with dementia.

Lena Hallengren, Swedish Minister for Children, the Elderly and Gender Equality
What do you see as the biggest priority and the biggest challenge in the fight against dementia in Sweden?

The Government believes that knowledge about existing legislation must be increased in order for people in need of coordinated care to be able to get the right care throughout the care pathway.

In Sweden there is a shortfall of healthcare staff of approximately 130,000 people to adequately meet the future demographic challenges and to care for the ageing population.

The Swedish Dementia Strategy does not have a designated budget or “targeted” funds specifically to realise its content. However, the municipalities and county councils will receive SEK 8 million in 2018 to develop materials and train staff in coordinated person-centred planning throughout the care pathway.

At present, there is a gap between social care services and psychiatric care of dementia and we wish to ensure that elderly people and people with multiple illnesses with high coordination needs (for example a person with Down’s syndrome and severe stage dementia) receive the right help regardless of whether they are in county councils or municipalities.

The Swedish Dementia Strategy will also safeguard integrity for persons with dementia. That notion of integrity includes the staff working with people with dementia, hence forthcoming financial support will be allocated to develop dementia quality registers. In addition, the Swedish Centre for Dementia receives SEK 2 million to provide information materials and tools for those who provide care and support for people with dementia.

The purpose of the materials is to improve communication and coordination. The work will be done in partnership with the Swedish municipalities and the National Board of Health and Welfare. The information materials and tools will be available on the Swedish Dementia Center website and will be free of charge for health and medical personnel.

Under key area number seven of the dementia strategy work plan “technology as a part of health and welfare”, it is expected that technology should be utilised as a tool for staff and patients. There is a need to learn and listen very carefully about IT and technology to meet the needs for future care, especially for the elderly. However, that should be done to increase individual integrity of patients and staff; any integration of technological tools related to the direct physical care of patients must be done slowly, stepwise and thoughtfully.

Therefore, although technology is at the forefront in Swedish business life, it is not a substitute for humanity or caring. The Swedish Dementia Strategy does not contain any targeted plan or budget for new IT infrastructure or the development of new IT tools.

“Although technology is at the forefront in Swedish business life, it is not a substitute for humanity or caring”

When deciding to proceed with the strategy, you consulted with neighbouring Nordic countries who already have successful dementia strategies in place. What lessons did you learn?

The current National Guidelines for Dementia developed by the Swedish Board of Health and Welfare are the underlying foundations of the future Swedish Dementia Strategy. As Olivia Wigzell (Director-General of the Swedish National Board of Health and Welfare) is Sweden’s representative in the Executive Board of the World Health Organisation, the key areas of the future strategy are fully in line with the work of the World Health Organisation on dementia.

I am also very open to continue talking to my Nordic colleagues in the future and collaborating with them on work for people with dementia.

Do you think there is a need for closer co-operation on dementia at European level and between Member States?

Yes. As already mentioned, the Swedish Government supports the work on dementia and many other health and welfare issues concerning the ageing population which is coordinated by the World Health Organisation.

In Sweden, dementia is often mentioned as a disease of the elderly, but the Swedish Government knows of course that ageing is a risk factor for neurodegenerative diseases, not a cause.

The current Swedish Dementia Guidelines underline that dementia symptoms evolve most often at an older age. From that concept, the Swedish government can maintain a focused dialogue about dementia with the communities about nursing home resources, with emphasis on security and integrity, as well as in accordance with tax funding and distribution of means in the Swedish health system. This means that people with dementia may fall under the category of “elderly” in future.

How important is the Government’s relationship with the Swedish Alzheimer’s Associations?

Alzheimer Sverige and Demensförbundet have a close relationship with the Swedish Board of Health and Welfare and also with the Swedish Centre for Dementia. They have been part of the development of the current Swedish National Guidelines for Dementia, therefore these organisations will have also have voice in the future Swedish Dementia Strategy.

Profile

Lena Hallengren serves as Minister for Children, the Elderly and Gender Equality since 8 March 2018. She has been a member of the Riksdag since 2006 and previously served as Deputy Minister of Education from 2002 to 2006. 

@lenahallengren

Dementia in Europe 25
Lilly and Alzheimer’s Disease

For nearly 30 years, Lilly has been committed to Alzheimer’s disease research and development. During this time we’ve made significant scientific advances and we’re not slowing down. In fact, our commitment is stronger than ever. Through perseverance and discovery, our goal is to make life better for those affected by Alzheimer’s disease around the world.
“Resilient” is perhaps the best word to define Alzheimer associations and people involved in promoting the quality of life and legal rights of people living with dementia.

Since 2006, when Alzheimer Portugal, together with all Alzheimer Europe member associations at the time, signed the Paris Declaration, we have been working hard to make dementia a national public health priority. As some of you may recall, the 17th Alzheimer Europe Conference “The Sound of Silence” took place in May 2007 in Estoril, Portugal and was attended by a number of policy makers, including a representative of the Presidency of the Portuguese Republic who endorsed the Paris Declaration.

In advance of a conference held by the Calouste Gulbenkian Foundation (on the theme of “Alzheimer Disease – Which Politics?”) in October 2009, Alzheimer Portugal prepared a document called “Alzheimer’s National Intervention Plan”. The plan inspired some political initiatives towards the recognition of dementia as national priority around the following priority areas:

1. Better quality of life for people living with dementia and their carers, including issues related to pharmacological and non-pharmacological interventions, social support, facilities and services, through the implementation of health and social policies specific for people with dementia.
2. Research on the causes, prevention and diagnosis of Alzheimer’s disease, as well as the collection of epidemiological data.
3. Creation of a legal framework defining the legal rights of people with incapacity, including a legal framework for care, intervention and research.

Now, in 2018, when Alzheimer Portugal is celebrating its 30th anniversary, we are pleased to be able to share some of our recent achievements.

**Health Strategy for Dementia**

In June 2018, the Health Ministry launched the “Health Strategy for Dementia”, which is the result of the recommendations included in the “Bases for the Definition of Public Policies in the Field of Dementia” to which Alzheimer Portugal contributed.

The Strategy sets out the principles of care for people with dementia, criteria on prevention, early detection, availability of clinical and comprehensive diagnosis, therapeutic intervention at primary care level, hospital and specialised care, a care pathway based on the ethical principles of proximity, availability, equity and continuity. The Strategy is a very promising document, however, it is focused only on the health care system and does not include social and legal perspectives.

Alzheimer Portugal will now participate in the National Health Plan for Dementia Coordination Group led by António Leuschner. This Coordination Group will be responsible for the development of accompanying Regional Dementia Plans that, within a year, will have to launch measures on dementia adapted to the specificities of each Region. The measures must be prepared in accordance with the National Health Plan and the National Mental Health Plan.

As a clear evidence of the importance of the work that Alzheimer Europe has been doing and how it influences national policies, it is useful to highlight that the Act for Government includes several references to important Alzheimer Europe resources, including:


**“Dementia Friends” Campaign**

Under the High Patronage of His Excellency, the President of the Republic, Alzheimer Portugal launched its Dementia Friends Campaign on 30 July coinciding with International Friendship Day.

In 21 different places in the country, ranging from beaches to city squares, from the north to the south and islands of Portugal, 180 Alzheimer Portugal volunteers invited people to become dementia friends by following four steps:

2. Register on the website.
3. Watch a video to learn more about dementia.
4. Commit to one concrete action (such as becoming a volunteer with Alzheimer Portugal, not using words like “demented” or making friends, colleagues or family aware about dementia).

This is a nationwide awareness campaign aimed at reducing stigma and changing the way people think, talk and act about dementia. It shows that it is possible to live well with dementia and demonstrates that there is much more to a person with dementia than their condition.
The campaign has the support of the UK Alzheimer’s Society and is sponsored by different organisations, including many municipalities. It will last till the end of 2020 and it is expected to reach 60,000 dementia friends.

At national level the campaign is a significant contribution to raising awareness and is in line with the aforementioned Health Strategy for Dementia, which recognises the need to develop awareness campaigns in order to combat against a lack of knowledge among the public.

The launch of the Dementia Friends campaign went well with good media coverage from TV, radio and newspapers, as well as the involvement from Alzheimer Portugal staff and volunteers, with lots of photos and positive reactions to the initiative being shared on social media. The next Memory Walk that takes place in September in 67 different locations will represent a huge opportunity to invite and gather more Dementia Friends.

Immediately before the launch of the campaign, a survey was conducted about the perceptions people have on dementia in Portugal with the support of the Directorate General of Health. This will allow for a comparison of the awareness about dementia before and at the end of the campaign.

**Legal Rights of People Living with Dementia**

As can be seen from the Dementia in Europe Monitor (Alzheimer Europe, 2017), Portugal has signed and ratified the main International or European Human Rights Treaties, including the UN Convention on the Rights of Persons with Disabilities (UNCRPD). However, this is in itself not enough to truly promote the legal rights of people with disability, including people with dementia.

Alzheimer Portugal was therefore delighted to welcome new legislation on the promotion of autonomy of people with incapacity, approved in July 2018 by the Portuguese Parliament and published on 14 August.

This legislation is an initiative of the Government with the special involvement of the Minister of Justice and will come into effect on 1 February 2019. The Act, inspired by the “Betreuungsgesetz” of German Law, will end the approach of “interdiction” and “incapacitation” as previously applied by the Civil Code of 1966. Instead, a legal framework promoting greater flexibility and autonomy will apply. It complies with the UNCRPD, particularly in relation to Article 12(4) which states:

> “States Parties shall ensure that all measures that relate to the exercise of legal capacity provide for appropriate and effective safeguards to prevent abuse in accordance with international human rights law. Such safeguards shall ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person, are free of conflict of interest and undue influence, are proportional and tailored to the person’s circumstances, apply for the shortest time possible and are subject to regular review by a competent, independent and impartial authority or judicial body. The

We believe that the Dementia Friends campaign will play a significant role in the way people think, talk and act in relation to dementia.”
POLICY WATCH

safeguards shall be proportional to the degree to which such measures affect the person’s rights and interests.”

This is evident in the new legislation which makes provisions for persons to choose, in the judicial process or in advance, who they want to help or represent them in the different areas of their life, including in relation to personal issues, health care, finances and property etc.

In addition, the law also states that the decision of the court shall take into account any living will and/or health care proxy, and that the individual’s preferences expressed in advance must be respected.

Alzheimer Portugal is very happy with this important step forward for the effective promotion of the legal rights of people with dementia. This area will be one of the key themes to be explored at our conference (“A holistic perspective of dementia”) which will take place in Lisbon on 22 and 23 November 2018 to celebrate our 30th anniversary. The participation of the Minister of Justice, Francisca van Dunem is already confirmed.

Conclusion

In Portugal, 2018 has been an incredibly important time for the launch of key political and legal measures towards a more dementia friendly society in line with the global and European dementia movements.

We hope that the coming years will see these excellent initiatives put into practice with a strong focus on training and awareness, with further developments taking place such as the establishment of professional guardians. Indeed, this latter issue is crucial as there are large numbers of people with incapacity with no guardian, living alone in poor conditions (e.g. lacking food, poor hygiene etc.) because there is no one to be appointed to protect them and to act on their behalf. The new legislation does not resolve this issue.

Alzheimer Portugal is very proud of being recognised by the Government as a real partner in the development and implementation of policies and legislation that are meaningful for people with dementia and carers.

We believe that the Dementia Friends campaign will play a significant role in the way people, including political decision makers, health, social care and legal professionals, think, talk and act in relation to dementia. This will be significant in the implementation of the Health Strategy for Dementia and the new legal rights legislation.

Profile

Maria do Rosário Zincke dos Reis has been practicing law in Portugal since 1987, with a focus on family law and the legal rights of people with incapacity. She served as Chairperson of Alzheimer Portugal between 2001 and 2012 and currently she is a Board member and a volunteer especially focused on training and lobbying. Rosário has been a member of the Alzheimer Europe Board since 2008 and the Honorary Treasurer since 2010.

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French decision to stop the reimbursement of Alzheimer’s medicines comes under fire

As of 1 August, medicines for the treatment of Alzheimer’s disease will no longer be reimbursed in France. Alzheimer Europe discusses the consequences of this decision with Pierre Krolak-Salmon, President of the French Federation of Memory Centres.

According to the French “Haute Autorité de Santé” (HAS), the current medicines for the treatment of Alzheimer’s disease have an “insufficient” efficacy for them to be reimbursed. How do you assess the efficacy of these drugs?

These drugs have been scientifically assessed thanks to large scale international randomised controlled trials. All published studies and meta analyses were in favour of the effectiveness of the these drugs for a symptomatic effect on cognition in patients with Alzheimer’s disease, Lewy Body disease and cognitive disorders of Parkinson disease. These drugs were then given a marketing authorisation in the light of a satisfactory answer to effectiveness criteria established by the regulatory agencies such as the Food and Drug Administration (FDA) and the European Medicines Agency (EMA).

The clinical effect of these drugs is small when considering them alone. However, they build up a synergy with non-drug therapies. Over the last twenty years, many help and support programs were developed in Europe for patients and caregivers which promoted and strengthened the synergy of medical and social approaches. Only an interdisciplinary approach including the general practitioner, the specialist physician of neurocognitive disorders, the paramedical professionals such as the speech therapist, psychologist, occupational therapist, psychometrician and/or nurse can be efficient. In addition, social services coordinate the home care plan tailored to the dependency needs of the person and family associations support the patients and their relatives. This comprehensive approach reduces the impact of the loss of autonomy and enhances the “well-being” of the patient and his/her relatives, which is the goal of this approach.

The use of these drugs is part of this care pathway. All the therapeutic measures and support contribute to the slowing down of the patient’s cognitive, functional and behavioural impairments.

Apart from the limited efficacy, experts highlighted the risk profile of these medicines as another reason to stop their reimbursement. How dangerous are these drugs?

Their tolerance profile has been known for almost 20 years and is consistent with what is expected. No negative or dangerous pharmacovigilance signal was reported by the health authorities of western countries. Furthermore, no national or European health safety agency whose aim is to assess the benefits/risks of drugs questioned the safety of these products.

The positive benefit/risks ratio has been recently confirmed by some meta analyses (Tan et al., 2018, Isik et al., 2018), a Cochrane review (Birk and al., June of 2018) and the National Institute for Health and Care Excellence in the United Kingdom (June of 2018).

Unfortunately, we have to say that this level of evidence is currently not reached by the psychosocial interventions, but we miss scientific study design adapted to non-pharmacological interventions.

The French Federation of Memory Centres has campaigned against the decision of the French Health Minister. How did other organisations react to this decision and what are the next steps in your campaign?

The main French scientific and medical societies and professional associations* joined us, as well as France Alzheimer and France Parkinson. Numerous articles were published and interviews were given at a national level. All these organisations shared their deep disagreement regarding this unfair decision. A court action has also been launched with an appeal made to the “Conseil d’Etat” which has the support of all the organisations.

In your experience as a doctor treating people with Alzheimer’s disease, what has been the reaction of people affected and their family members to this decision?

They do not understand. A particular concern is the point regarding the “danger” that has been reported by the High Authority of Health, and the fact that their medical doctor (whom they trust) did not mention it apart from mentioning possible and usual side effects. On the whole though, they keep on trusting us and ask for advice on whether to keep on taking these drug or not.

But, some people will face some real financial issues, as these expenses for medicines will now be added to all the other costs linked to the disease.

How is the reimbursement situation of these medicines in other EU countries?

To my knowledge, only 2 or 3 countries do not reimburse at least one of the 4 listed drugs. These countries did not develop any national plan regarding AD and dementia.

You coordinate the work of the 2nd EU Joint Action on Dementia on timely diagnosis. Do you fear that decisions such as these could further delay the diagnosis of Alzheimer’s disease in France?

This is definitely not a good signal for detection of neurocognitive disorders in primary care and for co-working with specialists to provide an etiological diagnosis as well as tailored post-diagnostic support. Therefore, all the medical societies and organisations, as well as professionals and informal caregiver associations like France Alzheimer keep on fighting.

Fortunately, we have a very good dialogue with the French GP community, especially with the “Collège de Médecine Générale” regarding the need for a better detection of neurocognitive disorders in primary care. A French paper (and a European paper in preparation) has just been co-signed to propose a graduated and tailored diagnosis strategy involving the GP from the beginning to post-diagnostic support, including access to research and especially clinical trials. This strategy fits within the frame of the French national plan of neurodegenerative diseases and the European Joint Action “Act on dementia” financed by the European Commission.

Alzheimer Europe and its member organisations condemned the decision of the French government to exclude current medicines licensed for the treatment of Alzheimer’s disease from the reimbursement system.

The organisation also expressed grave concerns about the sensationalist and scientifically baseless media coverage in some media claiming that these drugs “killed more people than they ever helped”.

Whilst recognising that these medicines “only” provide symptomatic relief for a group of patients for limited periods, Alzheimer Europe reiterated its position for the continued reimbursement of these drugs:

- No significant safety issues have been identified through the pharmacovigilance system of the European Medicines Agency.
- The existence of these medicines has contributed to the development of dementia care through an expansion of memory clinics and other specialised services offering timely diagnosis, advice and support for people with dementia and their carers.
- The discontinued prescription of these medicines would take away one of the main reasons for people coming forward for an early diagnosis of their condition who would therefore no longer benefit from other significant advantages of an early diagnosis.
- European citizens should have equal rights to protection and access to health care regardless of their country of residence and Alzheimer Europe regrets that people with Alzheimer’s disease in France are excluded from accessing medicines reimbursed in other European countries.

Therefore, Alzheimer Europe and its member organisations fully support the campaign and online petition of France Alzheimer which calls for the continued reimbursement of these medicines.

Profile

Professor Pierre Krolak-Salmon is a neurologist and geriatrician and Head of the Memory Centre of Lyon (France) and the Clinical Research Center “Elderly, Brain and Frailty”. He teaches at the University Claude Bernard Lyon 1 and is the current President of the French Federation of Memory Centres. He coordinates the work package on timely diagnosis and post-diagnostic support of the 2nd European Joint Action on Dementia.

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Quality of dementia care in OECD countries under the microscope

On 12 June, the Organisation for Economic Co-Operation and Development (OECD) released a report entitled “Care needed – Improving the lives of people with dementia”. Alzheimer Europe catches up with Elina Suzuki, Health Policy Analyst at OECD to discuss the main findings.

The OECD report on the quality of dementia care was launched on 12 June 2018. However, the organisation has been active in the field of dementia prior to that. Could you highlight some of the previous key initiatives of OECD in the dementia field?

The OECD has been working in the dementia field for quite a while. In recent years there has been an increased focus on international engagement and collaboration around dementia, including the G8 Dementia Summit in London in 2013, and the first Ministerial Conference on Global Action Against Dementia in March 2015. We’ve been actively involved in these processes and have been engaged in research throughout, including publishing our 2015 report Addressing Dementia: The OECD Response and working to develop better internationally comparable indicators for dementia. International collaboration is critical to drawing attention to dementia and making progress towards better dementia care and research. We want to be a part of this, and I think our strengths, both in terms of research and our role as a forum where governments can exchange knowledge and develop solutions to common problems, means we’re well-placed to do so.

Your 2018 report highlights the growing human and financial cost of dementia for society. What were the main findings in that regard?

Across the OECD today, it’s estimated that about 19 million people are living with dementia. But dementia doesn’t only affect them. The lives of their friends and family members – many of whom support them as informal carers – are also deeply impacted by the diagnosis. Without the development of a cure or a disease-modifying treatment, it’s expected that nearly 41 million people will be living with dementia by 2050. Already in 2018, the cost of dementia exceeded 1 trillion USD around the world for the first time. It’s clear this is a growing problem that we can’t ignore.

Are countries getting better at detecting and diagnosing dementia?

On the positive side, many countries have begun to recognise the importance of giving someone a diagnosis, and the attention on facilitating more timely diagnosis has certainly grown across many countries. Yet we also found that many countries remain poorly prepared to diagnose dementia, despite this increased policy attention. For example, fewer than half of OECD countries can even estimate national diagnosis rates. How can you be sure you’re diagnosing more people, when you don’t know how many are being diagnosed to begin with? We also found that many countries remain poorly prepared to diagnose dementia, despite this increased policy attention. For example, fewer than half of OECD countries can even estimate national diagnosis rates. How can you be sure you’re diagnosing more people, when you don’t know how many are being diagnosed to begin with? We also found that many countries have emphasised a larger role for primary care services in both detecting and diagnosing dementia. Yet despite this, very few countries have developed policies or programmes to strengthen the capacity of primary care physicians to diagnose well, or offered financial or other incentives for them to undertake training and professional development that would enable them to do so. There’s definitely been progress made in working towards a more timely diagnosis, but we’re still a long way away from where we want to be.
A number of countries are developing dementia-friendly or dementia-inclusive initiatives. How widespread have these initiatives become and do they positively impact people with dementia?

We were encouraged to find that dementia-friendly or dementia-inclusive initiatives have been launched in over 90% of OECD member states. These initiatives are critical to helping reduce stigma and improve quality of life in the community for people living with dementia. And we’ve seen dementia-friendly initiatives launched across many different parts of the community, from training police forces and fire departments to be dementia-friendly, to large businesses that train their staff to become dementia friends or dementia-friendly transportation and construction methods adopted. This is an area where we think there’s a real opportunity for governments to signal their support for improving dementia care and have a real impact. In many cases, we’ve seen dementia-friendly initiatives develop out of the tireless work and goodwill of committed individuals or local organisations. Their role is indispensable. But it also means that whether you live in a dementia-friendly community can be determined by whether or not you have strong advocates living in your area.

What were your findings as to the quality of care for people with advanced dementia?

Unfortunately, the quality of care for people living with dementia remains in many cases very poor. Care workers rarely receive the training they need to address the needs of people living with dementia, and the majority of people with dementia in care facilities live in homes that aren’t designed to meet the needs of people living with dementia. For our report, we also collected new data that underscores how poor the quality of care for people with dementia can be. Though there is broad clinical agreement that antipsychotic medications should not be used for people with dementia in almost all cases, we found that rates of antipsychotic prescribing nevertheless vary by a factor of more than two across the OECD, suggesting that this practice is still widespread in many countries. One in 20 people 65 and over received a prescription of antipsychotics in 2015 in OECD countries. This rate is far too high.

We hope that measuring this and other quality of care indicators can help countries to better monitor improvements in quality of care going forward. We also found that the quality of care in hospitals is often poor for people with dementia. It’s important that where someone has been diagnosed, hospitals know about this diagnosis, and that their staff is trained to respond appropriately.

What are the next initiatives which OECD will undertake in the field of dementia?

We’re currently developing a policy brief that looks back on the progress OECD countries have made over the last five years, since the 2013 G8 Summit on Dementia. We’re also continuing to push forward with developing internationally-comparable indicators of dementia, including indicators to improve the quality of care. I think we’ve seen a lot of momentum internationally in the last few years, and we look forward to building on that.

Profile

Elina Suzuki is a health policy analyst in the Directorate for Employment, Labour and Social Affairs of OECD. She co-wrote the OECD report “Care needed – Improving the lives of people with dementia” together with Tim Atkins.

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Patient and Public Involvement: Moving from proving to improving

Anna-Louise Smith, Research Engagement Manager of Alzheimer’s Society shares her organisation’s experience in involving people affected by dementia in research.

Since 1999, Alzheimer’s Society has pioneered the active involvement of people affected by dementia in research through our award-winning Research Network. We are leaders across medical research charities in the way we facilitate patient and public involvement.

Patient and public involvement (PPI)

PPI in research is a philosophy whereby research is carried out “with” or “by” people affected by the condition rather than “about”, “for” or “to” people. Over the past twenty years an increasing value has been placed on including the lived experience of patients and the public in research covering the full spectrum of basic science through to healthcare services.

People with the lived experience of a condition bring their unique expertise to the research process. More and more researchers are now including PPI in their research, not just because funders tell them to, but because they believe that it’s the “right thing to do” and improves the quality and relevance of their work.

We support PPI not just for our own funded research, but also across dementia research in the UK and internationally.

The impact so far

It’s clear why the Research Network is valued so highly across the dementia research field. Many of Alzheimer’s Society’s achievements in research have come about due to the contributions of our dedicated volunteers.

Over the past 20 years our Network has been at the forefront of making improvements including: campaigning for NICE (the National Institute for Health and Care Excellence), widening access to treatments, increasing the focus on reducing antipsychotic use, lobbying for more research into improving care and implementing research into practice.

Researchers have told us about the value they place on the contributions of the Research Network. In our impact report, researchers explain that volunteers have provided input on identifying the best research outcomes to measure and improved recruitment to research studies. Volunteers have also helped researchers with data collection and analysis and they have supported research teams to communicate their research results most effectively.

Providing the evidence

In 2017 we decided to collect some of the evidence that we had heard anecdotally and produce our first ever impact report for PPI. We surveyed and interviewed members of the Research Network and researchers across the UK.

Following this we identified 5 important areas that have been impacted by contributions from our Research Network: Society, Researchers, Volunteers, Research and Alzheimer’s Society.

Researchers explained how Alzheimer’s Society helped them to learn about the importance of PPI, and how to go about involving people meaningfully and effectively. In our report, Mario (a biomedical researcher) stated that he had previous involvement experience. However funding from Alzheimer’s Society provided him with the opportunity to combine his research with his involvement skills, and he has become a key advocate for the approach. Mario thinks that involvement has...
particular benefits for early career researchers: “We need to continue working, educating our new researchers and ourselves as to how we can best incorporate these activities and evidence in our actions. It is really relevant.”

This was reflected by the views of volunteers affected by dementia, such as Kieran:

“If research doesn’t have any practical implications, then it is research for research’s sake – is it going to help? Is it going to make more of a difference?”

Ensuring that research funded by Alzheimer’s Society makes a difference to people affected by dementia is a crucial aspect of the volunteer role.

Our report found that there is overall recognition of a positive shift in researcher attitudes over time towards patient and public involvement (PPI). Despite this progress, the online survey revealed that PPI was seen as less influential in biomedical research than in care research. The case studies, however, demonstrate that there is a place for the Research Network in biomedical research, particularly in contributing to effective communication, accessibility and defining research impact.

The evidence around PPI in dementia research is growing but there is still a need to improve the evidence in the academic domain. We have partnered with the journal Dementia to guest edit an edition due for publication in November 2018 to tackle this issue. It will bring 9 new articles into the academic literature sphere that will articulate the impact of PPI. Crucially, this will also help all involved in dementia research to face the challenges in delivering dementia research.

Moving forward

We want researchers and people affected by dementia to unite in partnership. Together, they can ensure the research we support will have the best chance of making a meaningful difference to people’s lives. The Research Network is open to new recruits so there’s never been a better time to get involved.

Alzheimer’s Society now aims to increase the number of people with dementia volunteering in the Network, as well as the accessibility of all Research Network volunteer roles. As the Network grows, we will continue to assess these impacts, to understand which methods of involvement achieve the best impact. We will make our evidence base publicly available to support shared learning and a greater understanding of best practice in PPI in both care and biomedical research.

The diagram below demonstrates how volunteers influence the research programme throughout all stages:
Otsuka: Proud to take the road less travelled

Today, more than ever, addressing unmet medical needs for people living with long term illness must go far beyond the conventional. In central nervous system (CNS) disorders, there is still a lot that isn’t understood, and developing new treatments is a challenge. As a pioneer with a venture company spirit, we work with global partners to develop innovative new options in under-served areas such as Alzheimer’s disease.

We see treatment with medicines as only one part of the total care package. From ingestible sensors* to data analytics*, we are also exploring how digital healthcare* technology can help our patients, caregivers and healthcare professionals.

*under development and not available yet

Our mission is clear. We are pioneers in neuroscience.

We’re proud to partner with Alzheimer Europe


Founded in 1978, Biogen is one of the world’s oldest independent biotechnology companies.

www.biogen.com
In Ireland today there are 55,000 people living with dementia and research shows that people with dementia can struggle to eat properly and may not eat or drink well to support their needs and well-being.

Research which was carried out by Ipsos MRBI and commissioned by Nutricia Advanced Medical Nutrition and The Alzheimer Society of Ireland (ASI), found that the difficulties people with dementia are experiencing include the person forgetting to eat (58%), forgetting they have eaten and eating again (54%), finding it difficult to finish meals (35%) and being too tired to eat (36%).

The research also found that a majority of survey respondents reported a change in their sense of taste (59%) and smell (56%), while 54% found it difficult to finish meals (51%) and 44% in swallowing food.

Further findings revealed that 70% experience weight changes and 60% report changes in appetite, following diagnosis with dementia. 37% of respondents had a weight increase and 34% a decrease. 32% reported a decrease in appetite and 28% an increase.

The initial research also highlighted challenges with shopping and cooking. 82% reported that it could be difficult to get to the shops for food. 88% that shopping can be confusing and 70% that family and friends may manage shopping on their behalf.

The research reported that very few (6%) retained a role in meal preparation following diagnosis and stated that more than half (54%) had not actively searched for information on managing diet and nutrition following diagnosis.

Practical tips in new “Eating well with dementia” booklet

Following on from the research, a new booklet has been developed for families and carers in Ireland called “Eating well with Dementia”. This booklet, which was launched in September 2017, offers practical tips and helps families and carers to understand how dementia can affect a person’s appetite and experience with food.

Eating well with dementia also looks at how to meet nutritional needs of someone with dementia; how people with dementia can enjoy and be involved in meal preparation and mealtimes; and how to deal with weight loss, weight gain and other nutritional issues.

Basic tips, which are included in the booklet, including keeping the table setting simple, establishing a routine, allowing sufficient time to eat, being flexible around food choices and not worrying about neatness, will be of huge assistance to family members and carers across Ireland.

The ASI’s Head of Advocacy and Public Affairs, Tina Leonard, believes that some of the tips that are contained in this booklet can ensure that people with dementia can get the nutrients that they need.

“Everyone who has dementia is different. Some people can struggle to eat enough throughout the day to meet their nutritional requirements, while others may forget to eat, thinking they have already eaten, or struggle to finish a meal,” she said. “This can all become more challenging as dementia progresses. Eating a healthy, balanced diet is essential to maintaining good health and following the tips in Eating well with Dementia will ensure that people are getting all the nutrients that they need.”

“Family and friends can play a key role. Some of the tips contained in this booklet include making sure that people with dementia have some company at mealtimes and that mealtimes are sociable and enjoyable events for all of the family. Other simple tips include encouraging people to eat finger food should using cutlery be an issue, or if people like to walk around during meal times.”

In total, 50,000 booklets were produced and are helping people with dementia all over Ireland. The brochure was distributed to 1,300 health display stands nationwide for
a six-month period, including GPs health centres and hospitals. It reached over 2,000 GPs and 1,100 Practice Nurses.

**Successful Launch**

During the week of the launch, the ASI Alzheimer National Helpline 1800 341 341 had a 66% increase in calls. In addition to this there was a huge reaction to the launch of the booklet in the national and regional media in Ireland. In total there were seven national media pieces and 14 regional pieces.

The booklet has proved a huge success with the book in huge demand since its launch winning research awards in November 2017 and also being presented to members of the Irish parliament in June.

**Awards**

In November 2017, Ipsos MRBI, in partnership with Nutricia Medical and the ASI, were successful in the Research Excellence Awards 2017 from the Marketing Society in two categories, Public Policy and Social Research and the overall Grand Prix winner. These awards, now in their ninth year, recognise market research excellence across the entire industry in Ireland and Ipsos MRBI retained its Grand Prix crown from 2016.

Judges commented that an extremely challenging context for research was addressed with an innovative, sensitive and meaningful methodology, with a great understanding of the challenges facing dementia patients in meeting nutritional needs.

At the time of the award, Director at Ipsos MRBI Tarik Laher said: “We are thrilled with this double award win, which is proof of the value, insight and methodological excellence that this research has delivered. It would not have been possible had people with dementia not shared their stories and opinions so openly and honestly and this win is a testament to them. We hope that the learnings from this project help lay the foundation for better nutritional care for those with dementia into the future.”

In June 2018, based on the success of the booklet, the Co-Conveners of the All-Party Oireachtas Group on Dementia Mary Butler TD and Senator Colette Kelleher hosted a Building Dementia Awareness event in the Oireachtas in Leinster House in Dublin on the topic of nutrition for people with dementia. The group believes that is an important element of dementia that the public needs to be

**Top tips for eating well with dementia:**

- Keep the table setting simple
- Establish a routine
- Distinguish food from plate
- Company at mealtimes
- Familiarity is important
- Be flexible around food choices
- Allow sufficient time
- Be flexible to food preferences
- Don’t worry about neatness
- Use finger food.

**All-Party Oireachtas Group**

In June 2018, based on the success of the booklet, the Co-Conveners of the All-Party Oireachtas Group on Dementia Mary Butler TD and Senator Colette Kelleher hosted a Building Dementia Awareness event in the Oireachtas in Leinster House in Dublin on the topic of nutrition for people with dementia. The group believes that is an important element of dementia that the public needs to be
aware of so that we can have fully considered policies and funding for appropriate services and supports.

At the awareness session in June Tarik Laher from Ipsos MRBI spoke about research outcomes; member of the Dementia Carers Campaign Network (DCCN) Ray Cregan spoke about caring for his father, Paddy; Tracey Waldron Senior Dietician, Medicine for the Elderly, St James’ Hospital in Dublin spoke about nutrition and dementia.

The meeting was attended by 21 members of the Irish Parliament who were all very interested in the topic and campaigning on the key issues that were raised.

The ASI is currently linking in with our colleagues in the Czech Republic Česká alzheimerovská společnost, o.p.s. to explore how we can share this work.

The booklet is available through the ASI’s Alzheimer National Helpline and as a download through the ASI’s website and still continues to provide people with dementia and their family carers with essential tips for eating well with dementia.

“Dementia can affect taste, smell and thirst senses and sometimes people find that not only recognising food can be difficult, but identifying cutlery can be a problem too,” said former family carer and advocate, Ray Creagan.

“So there are lots of little things that we all take for granted that need to be taken into consideration. Eating well with Dementia is of huge help to carers who are just looking for small, practical tips to ensuring that their loved ones get the best nutrition available to them and continue to eat well.”

**All-Party Oireachtas Group on Dementia**

The All-Party Oireachtas Group on Dementia was launched in 2016 and is run in partnership with the ASI who provides a secretariat along with expert advice to the group. The group was established amid growing concerns across the political spectrum of an expected trebling of numbers of people set to develop this challenging condition over the next three decades and the urgent need to plan for this eventuality now.

The group examine a number of specific areas including building understanding, consensus and cross party support for long term planning and increased investment to support people with dementia and their carers. TDs and Senators from across the main parties, as well as Independents, have joined this group.

**The Alzheimer Society of Ireland**

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The Alzheimer Society of Ireland
Dementia Friends: an initiative gaining support across Europe

Sarah More from Alzheimer’s Society presents Dementia Friends and how the idea is spreading across Europe.

What is Dementia Friends?

Dementia Friends is the biggest ever initiative to change people’s perceptions of dementia. It aims to transform the way people think, act and talk about the condition. The volunteer-led movement tackles the stigma and discrimination people with dementia can face globally. Dementia Friends take action, big and small, to support those living with dementia to feel supported and included in their communities.

There are now 40 members of the Global Dementia Friends Network working in different countries to change attitudes towards dementia on a global scale. With over 14.7 million Dementia Friends around the world, together we are part of the world’s biggest social action movement on dementia, raising awareness and challenging stigma.

Following the adoption of the WHO Global action plan on dementia 2017–2025, Dementia Friends is a powerful tool to enable Member States to work towards the target that “50% of Member States must have at least one dementia-friendly initiative by 2025”.

How did Dementia Friends begin?

Alzheimer’s Society was greatly inspired by the way Japan has raised awareness of dementia through their volunteering programmes, namely the Ninchisho (Dementia) Supporter Caravan programme. The UK government was keen to develop a similar campaign that would increase volunteer action as well as contributing to the Prime Minister’s Challenge on dementia (its national dementia strategy). With this inspiration, Alzheimer’s Society created the Dementia Friends programme in 2013 to help raise understanding on an individual level and encourage social action.

What has been the impact of Dementia Friends in England and Wales?

Dementia Friends in England and Wales has now reached over 2.6 million people since its launch and has been shown to play a significant role in supporting a societal shift towards acceptance and inclusion of people affected by dementia. This breaks down to 1 in 30 people in England and Wales committing to action on dementia! The results of a 2016 Dementia Friends impact survey showed that 86% of people felt that they had a better understanding of dementia through Dementia Friends and that 84% of people believed that Dementia Friends was inspiring communities to take action. The next goal is to create 4 million Dementia Friends by the end of 2020 and also to increase the social action element of the programme.

Why has Dementia Friends been so successful?

• Simplicity – Dementia Friends and its key messaging aims to challenge the misconceptions people hold about dementia and change public opinion in an easy-to-understand and engaging way.

• Accessibility – Dementia Friends are created via face-to-face Information Sessions,

Dementia Friends five key messages:

• Dementia is not a natural part of ageing.

• Dementia is caused by diseases of the brain.

• Dementia is not just about losing your memory.

• It’s possible to live well with dementia.

• There is more to the person than the dementia.

To become a Dementia Friend, a person needs to understand these five key messages and then commit to at least one action that will make their community a more dementia inclusive place.
an online video and through roll out with partner organisations. The range of routes available makes Dementia Friends accessible for a variety of audiences.

- **Replicability** – The Dementia Friends programme and activities can be easily replicated around the world. Countries are welcome to adapt resources to ensure cultural relevancy and understanding by local communities.

**How did Dementia Friends spread across Europe and the world?**

Given the success of the Dementia Friends model in the UK, Alzheimer’s Society committed to support other countries to develop and deliver their own Dementia Friends programmes or similar initiatives. One of the key commitments in the Prime Minister’s 2020 Challenge on Dementia, was for “England [to] lead the way in turning Dementia Friends into a global movement, including sharing its learning across the world and learning from others”. This commitment was confirmed at the WHO Ministerial Conference on Global Action Against Dementia in March 2015.

Over 80 countries attended the conference in Geneva. Dr Margaret Chan, the former WHO Director-General, made reference to Dementia Friends and a number of Alzheimer associations registered their interest in implementing their own national programmes. In 2016, Dr Chan became a Dementia Friend at a special Joint Dementia Friends/Ninchisho Supporter Caravan session on the margins of the G7 Health Minister’s Meeting in Japan – demonstrating the power of the programme to engage support.

**What is the Global Dementia Friends Network?**

The Global Dementia Friends Network unites countries who have committed to developing and delivering their own national Dementia Friends or similar programmes. As well as supporting countries to develop new Dementia Friends programmes, members are working together to share, support and collaborate for a truly global dementia-friendly movement championing the rights of people affected by dementia. Every country’s Dementia Friends programme is delivered in a unique way, depending on the cultural context and the size and capacity of the delivery organisation.

**What has been the reception for Dementia Friends in Europe?**

Europe is leading the roll out of Dementia Friends globally with 15 national programmes. These are: Bulgaria, Croatia, Denmark, England & Wales, Finland, Germany, Gibraltar, Moldova, Netherlands, Northern Ireland, Norway, Portugal, Scotland, Slovenia and Ukraine. Dementia Friends launches have recently been celebrated in Portugal and Norway (with the Norwegian Prime Minister becoming Norway’s first Demensvenn (Dementia Friend). Finland is in the process of finalising their launch to take place later this month.

Altogether there are almost 3 million Dementia Friends in Europe! By working together on Dementia Friends, Europe can become one of the most dementia-friendly places to live in the world.

<table>
<thead>
<tr>
<th>Country</th>
<th>Number of dementia friends</th>
</tr>
</thead>
<tbody>
<tr>
<td>Bulgaria</td>
<td>Launch TBC</td>
</tr>
<tr>
<td>Croatia</td>
<td>216</td>
</tr>
<tr>
<td>Denmark</td>
<td>60,666</td>
</tr>
<tr>
<td>Finland</td>
<td>162</td>
</tr>
<tr>
<td>England and Wales</td>
<td>2,646,459</td>
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<td>Germany</td>
<td>31,621</td>
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<td>Gibraltar</td>
<td>119</td>
</tr>
<tr>
<td>Moldova</td>
<td>Launch TBC</td>
</tr>
<tr>
<td>Netherlands</td>
<td>128,621</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>15,000</td>
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<tr>
<td>Norway</td>
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</tr>
<tr>
<td>Portugal</td>
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<td>Scotland</td>
<td>65,374</td>
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<tr>
<td>Slovenia</td>
<td>Launch TBC</td>
</tr>
<tr>
<td>Ukraine</td>
<td>Launch TBC</td>
</tr>
</tbody>
</table>

**Table 2: Number of dementia friends in European countries**

**Contact**

If you are interested in finding out more about the Global Dementia Friends Network or how to join, please contact Alzheimer’s Society via: dfinternational@alzheimers.org.uk
A look behind the headlines: What happens after the success of the first clinical trial of a disease-modifying treatment?

Alzheimer Europe interviewed Dr Anders Wimo from Karolinska Institutet, a member of the organisation’s Expert Advisory Panel to discuss the challenges awaiting the introduction of new disease modifying treatments for Alzheimer’s disease.

You recently published a provocative article in the Journal of Alzheimer’s disease entitled: “The End of the Beginning of the Alzheimer’s Disease Nightmare: A Devil’s Advocate View” in which you highlighted a number of challenges which would await us, if the first disease-modifying treatment for Alzheimer’s disease is approved. Are we close to such a treatment?

Recently, there have been quite a few high profile failures of phase III clinical trials of disease-modifying medicines. However, there are still many compounds in the pipeline and I am hopeful that we will soon see quite a positive and dramatic change of how we will be treating people with Alzheimer’s disease. At AAIC in Chicago recently, very promising results were presented from a phase 2B trial.

We also need to bear in mind though, that there will not just be positive developments on the treatment front, but also on the prevention front. A number of epidemiological studies and some intervention trials seem to indicate that prevention and risk reduction strategies can have and are having an effect.

Add to that that people are being diagnosed earlier in the disease process and that more and more people are able to lead meaningful lives after their diagnosis.

This all sounds very hopeful and positive! Why were you referring to a potential nightmare in your article in that case?

Let us have a look at the recent paradigm shift in the Alzheimer’s field. We now know that the actual brain pathology starts up to twenty years prior to any symptoms and that earlier interventions in the pre-dementia stage may have the highest chance of preventing or delaying the symptomatic phase of the disease. This shift means that we have potentially doubled or even tripled the numbers of people who may benefit from a treatment, as we will need to reach people at asymptomatic or very early symptomatic stages. At the same time, this poses the question of how to detect and diagnose people at these early stages.

There have been significant advances on how we can diagnose Alzheimer’s disease even in the prodromal and asymptomatic stages. Wouldn’t this help address the diagnostic question?

Biomarkers such as cerebrospinal fluid or PET scans for the detection of amyloid and tau have indeed revolutionised how we are able to diagnose Alzheimer’s disease. Please bear in mind though that these procedures are currently only being conducted in research centres and specialised memory clinics. We are thus having access and infrastructure problems in developed countries and these problems would be further exacerbated in low and middle income countries.

Since biomarker based diagnosis comes at a cost, couldn’t we reduce costs by careful screening and only applying those to people who would be most at risk?

It would indeed not be realistic or justifiable to carry out an extensive diagnostic battery on everyone. We need to find the right balance in terms of cost and effectiveness in making sure we correctly identify people with and without Alzheimer’s disease whilst also avoiding misdiagnosing people, particularly false positive cases.

We will definitely need more targeted approaches and I am happy to be involved in an IMI-sponsored research collaboration called MOPEAD which will look at which “Models of Patient Engagement for Alzheimer’s Disease” is the most effective in identifying people with prodromal AD and mild AD dementia. Once this project produces its results, we will hopefully have a better understanding of which strategies work best in identifying patients.

There are still many compounds in the pipeline and I am hopeful that we will soon see quite a positive and dramatic change of how we will be treating people with Alzheimer’s disease”

Anders Wimo

You have highlighted a number of challenges on how to identify patients who would benefit from new treatments. Do you foresee similar problems for the monitoring of treatment?

For the current medicines in the Alzheimer’s field, it is possible to start these drugs and continue them in primary care. With the new disease modifying medicines, it is not likely that general practitioners will be able to play this role. Therefore, the number of patients in memory clinics will increase considerably and they will undoubtedly have problems in managing and monitoring the treatment.
So far, we have discussed diagnostic and infrastructure issues. What are your views on the introduction of new treatments from a health economist’s perspective?

The costs of current treatments is really low since these drugs are now all available as generic medicines since the expiry of their patent. Any potential future disease-modifying treatment will of course cost considerably more. At this stage, it is difficult to evaluate the cost-effectiveness of such treatments, so I can ask a number of questions myself. How does short-term efficacy shown in a trial translate into long term clinical benefits such as delays in later institutional care needs? Will the cost savings be mainly in the social sector due to a reduced need for informal and formal care and will the cost mainly be in the medical sector? How will payers in one sector act if benefits occur in another sector much later in the course of dementia?

Within the framework of the International Pharmacoeconomic Conferences on AD (IPECAD), we are currently working on developing transparent open-source models to make these simulations and forecasts and to ensure the underlying hypotheses and scenarios can be easily understood and compared.

As a health economist, I have been involved in the development of a number of models and a recent simulation paper of a very positive disease modifying treatment which prevented the conversion from prodromal AD to AD dementia in 50% of patients showed no cost savings and surprised even us. This was mainly due to two facts since these treatments had to be given to patients during the mild cognitive impairment period where they incur few care costs and since these treatments actually prolonged survival time of patients.

With all the challenges you foresee, should we prioritise prevention over disease-modifying treatments?

In my opinion, there is no contradiction between prevention and disease-modifying treatments and we should of course pursue both strategies. Thanks to the FINGER study (Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability), we know that a multi-domain approach involving cardiovascular risk factors, nutrition and lifestyle can have a positive effect on cognition. However, we will need to confirm these results in other studies and to show whether these approaches will also have an effect on the risk of conversion to dementia.

Thanks for summing up the concerns you raised in your article as a “devil’s advocate”. Can you leave us with some positive outlook?

I have tried to highlight some of the challenges that will await the first company which is in the fortunate position of having a successful trial with statistically positive results. The challenges will be slightly different whether the results are clinically modest or more significant. In the latter case, there will quickly be a rising demand from patients, families and advocacy organisations, but also from the research and medical sector. As the budget impact would be enormous, a step wise introduction with filters is probably a way forward. At the same time, we could explore “conditional market approval” where the treatment could be approved under certain conditions, but where additional data on efficiency, support and cost-effectiveness would need to be presented later.

There is no contradiction between prevention and disease-modifying treatments and we should of course pursue both strategies

Anders Wimo

Profile
Anders Wimo is Adjunct Professor in Geriatric General Medicine at the Department of Neurobiology, Care Science and Society at the Karolinska Institutet.

Anders.Wimo@ki.se

Anders Wimo speaking at ADI Conference in Chicago (2018) (c) LaCour Images
CEAFA is a national non-Governmental Organisation in Spain which works to put dementia on the political agenda, seeking to secure the necessary societal commitments, by using its knowledge and experience to represent and defend the interests, needs and rights of all people living with dementia.

**The CEAFA network of associations**

The organisation is composed of 1 Confederation, 12 Autonomous Federations and 6 Provincial Associations that bring together more than 300 local associations which support people with dementia, their families and carers throughout Spain. Together, this network consists of 87,693 members, 3,983 employees and 5,208 volunteers.

In 1997, CEAFA was declared a Public Utility Entity. In 1999, the Ministry of Labour and Social Affairs awarded to CEAFA the Golden Cross of the Civil Order of Social Solidarity for its development of home care and assistance projects for people with dementia, as well as for its work to support families of people with dementia. In 2002, Her Majesty Queen Sofía of Spain accepted the position of Honorary President.

Lobbying for the recognition of dementia as a priority

More than 28 years of history supports the work and representations made by the Confederation. CEAFA is a reference entity at a national level for government agencies, private entities and society in general. It is not only committed to institutional representation but also to political action, operating and carrying out activities in order to influence national policies, encouraging a comprehensive approach to policies related to dementia.

VII National Congress of CEAFA in the presence of H.M. Queen Sofia, Malaga, 2017
Since 2010, CEAFA has campaigned at a national level on the need for an Alzheimer’s State Policy (National Dementia Plan/Strategy), embedded in policy for a set period of time and unaffected by any potential change in government. As a result of its work over the years, CEAFA is part of the National Dementia Group which is promoted by the IMSERSO (the institute for older people and social services – part of the Ministry of Health, Social Services and Equality) and which is coordinated by the Alzheimer’s State Reference Centre of Salamanca. In this group, CEAFA has played an active role in representing the collective views and concerns of its members.

“Since 2010, CEAFA has campaigned for an Alzheimer’s State Policy”

Jesús Rodrigo

The main objectives of the National Dementia Group are:

- To facilitate a network among the participating institutions.
- To establish common objectives for a comprehensive approach to dementia.
- To promote the exchange of knowledge, experiences and good practice among professionals.
- To communicate to society the progresses made in the fight against the disease and the improvements to people’s quality of life.
- To share information about plans, programmes and activities in dementia developed across the country, with the aim of coordinating socio-health actions in order to develop them at a state level in the field of dementia.

Raising awareness about dementia

Another activity of the body is to raise awareness among the population about dementia. One way in which this is done is through the annual World Alzheimer’s Day (21 September), during which a press conference is held, communicating the views and calls to action of the collective to the institutions and raising awareness in society. Calls for action are adopted by CEAFA and then taken to the different Institutions of the Autonomous Communities of the country.

At a societal level, CEAFA is committed to education and training on matters related to dementia, articulating how training may be cascaded to reach the largest number of people and groups possible. A knowledge base is continually updated to allow local/regional members of the Confederation to prepare and develop their own competencies, whilst allowing CEAFA, at a national level, to be recognised and valued as a reliable reference point in relation to the effects and consequences of dementia.

Every two years, CEAFA organises a National Congress with the aim of providing updated information to the main actors linked to the disease. In addition, the Congress provides a platform for networking, meeting and exchanging knowledge and experiences among the people who are part of the Confederation and wider society, helping facilitate a more coordinated and comprehensive approach to dementia.

Supporting research

Another strand of CEAFA’s work is to support basic and clinical research as a way of contributing towards finding a cure for Alzheimer’s disease and dementia. The organisation also works to support social research through social-health projects which seek to develop measures and tools that improve the quality of life for people with dementia, their families and carers. In order to conduct this research, many social researches have sought support and involvement from the confederal structure and our panel of experts.

These investigations have been made available to the institutions, to private companies and to society as a whole, serving as basic documents for consultation, information, training and practical application. Social research studies have allowed us to have a broad knowledge about the social reality experienced by people living with dementia and to propose measures for change.

Additionally, CEAFA works with numerous private entities in different social-health projects that allow us to know and to give visibility to the demands and needs of the collective. On many occasions, these have become proposals for change, support and action that are presented to government agencies to establish lines of action.

With regard to the role we play in society, CEAFA is committed to represent and defend all people affected by dementia. To achieve these ends, all of society must be involved and recognise the problems that dementia presents, not only at the present time, but also in the medium and long term. To this end, information and social awareness campaigns are promoted through holding events, including those on World Alzheimer’s Day, through the Alzheimer’s Disease National Congress, information and outreach days, street-level actions by AFAS etc.

“ It is essential that society becomes aware of the effects of Alzheimer’s disease”

Jesús Rodrigo

It is essential that society becomes aware of the effects of Alzheimer’s disease, to ensure that those in a position to resolve these issues do so in such a way as to ensure that society as a whole has a role to play, coordinated in such a way to ensure that they support the demand for dementia-specific plans and policies.

Profile

Jesús Rodrigo has been the Executive Director of CEAFA since 2005 and supports the Board of the Confederation. He is a member of the Coordination Committee of the National Dementia Group tasked with elaborating the National Alzheimer’s Plan. He also took part in the Technical Committee of the Neurodegenerative Diseases Strategy of the Health National System and is a Board member of Alzheimer Europe and Alzheimer Iberoamerica (AIB).

direccion@ceafa.es
Fundación Alzheimer España: “We fight to be remembered”

Our colleagues from Fundación Alzheimer España (FAE) give us an overview of the organisation’s history and current priorities.

Fundación Alzheimer España was created almost thirty years ago by a group of health professionals (researchers and medical specialists), lawyers and family members and promotes multidisciplinary training in the defence of the Alzheimer’s disease collective in Spain. Today, the Foundation is part of the Technical Committee of the “Strategy on Neurodegenerative Diseases” of the Spanish National Health System which will result in the future National Alzheimer’s Plan.

Among its statutory objectives, FAE wishes to promote the early detection of the disease, which allows to start working with the cognitive abilities of the patient and thus prevent their rapid deterioration. In addition, FAE wishes to design ad hoc projects and plans for each phase of Alzheimer’s disease.

For FAE, it is essential that patients and their families are not alone with this disease. It is therefore essential to promote active ageing and help to prevent dependence, as recommended by IMSERSO, the Institute for the Elderly and Social Services of the Ministry of Health.

FAE makes available to patients, their families, caregivers, professionals and society in general, a series of informative activities, training, technological innovations and resources focused on the disease. Some of the activities have been recognised by awards from institutions and prestigious entities, among which the Gold Medal of the Spanish Red Cross.

Our activities have been recognised by awards from institutions and prestigious entities, among which the Gold Medal of the Spanish Red Cross

In this sense, FAE carried out an ambitious and rigorous survey at a national level, with family caregivers of Alzheimer’s patients, with a sample that regrouped 1,402 respondents. One of the conclusions of this study is that what most alters the life of the caregivers are not the cognitive or memory disorders of the patients, but behavioural disorders. These occur in more than 90% of cases.

These behavioural disorders are revealed as the main cause of burden for caregivers and the main reason for institutionalisation. Apathy appeared as the most common disorder identified by families.

2. Mourning

FAE also carried out the first research project in Spain on the situation of caregivers of Alzheimer’s patients after the death of the family member they were caring for. This study was conducted in collaboration with the Department of Psychology of the Complutense University of Madrid. Amongst the conclusions, 30% of caregivers had to continue with the mental health treatments that they were prescribed before the death of the family member they cared for. Many of them continue with the support of a RESPALZ type programme during the mourning period.

3. The important role of non-pharmacological therapies

One of the objectives of FAE is to support family members and caregivers through workshops and training courses to address the disease at stage, as well as legal support, training for home help aides, volunteering, etc.

It is vital that patients maintain maximum autonomy possible in the activities of daily life. Different non-pharmacological therapies are being developed, with programmes such as group psycho-stimulation, comprehensive care programmes (JAPI), music therapy, RESPALZ, meetings between caregivers, shared play meetings, legal advice, etc.

FAE was a pioneer in Spain in carrying out with the support of the National School of Health (ENS) the first Alzheimer’s diploma for health professionals, from primary care physicians to nurses, etc.
In addition, FAE works in close collaboration with hospitals to help them attend, as far as possible, patients and their families within the framework of a public institution.

4. New technologies and virtual media

FAE launched an Internet radio programme dedicated exclusively to Alzheimer’s disease. This proved to be a particularly successful communication channel, which, in its 5 years of existence, had more than 100 programmes recorded with experts, as well as almost two million reproductions and downloads, both in Spain and Latin America.

This radio channel joins other communication actions carried out by FAE to raise awareness in society about the Alzheimer’s problem, such as press conferences and media campaigns, events, national and local actions to mark World Alzheimer’s Day etc.; thanks to the corporate social responsibility (CSR) programmes of private and public companies.

In addition to having a web page, social networks (Facebook, Twitter), FAE participates in different projects that rely on modern technologies to help patients and their families, as well as using them to encourage greater development in different areas of research.

FAE is also a founding member of HISPAROB, National Platform of Robotics and collaborates in the robotics project “Robalz” with the Carlos III University and the “Domalz” project, a home automation platform for improving the independence of patients at home. These projects will result in a series of tools aimed at maintaining the independence of the patient for longer and, at the same time, support and relieve the caregiver’s burden. These projects will be presented during the Conference.

FAE will continue to adapt to the evolution of knowledge about this disease, whether at the level of basic or psychosocial research, including new technologies, and, above all, adapting to the new profile of the 21st century caregiver.

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The political priorities of people with dementia in Spain

Ildefonso Fernández is a member of CEFAA’s Expert Panel of People with Dementia. In this article, he shares some of his personal experiences and highlights some of the political priorities of the group.

The Expert Panel of People with Dementia (known as PEPA by its Spanish acronym) was instigated by CEFAA and is comprised by a number of persons who have been diagnosed with Alzheimer’s disease at a younger age. In Spain, people with early-onset dementia now represent about 10% of the total number of people with dementia.

Until recently, the public perception of Alzheimer’s disease was of people at an advanced age. However, over 100,000 people in Spain have been diagnosed, just like me, during their professional career and find themselves confronted with the difficulties linked to the diagnosis prior to their retirement. The diagnosis therefore comes at a time in our lives where we still have a lot to say.

The moment of the diagnosis

A critical moment in the course of every disease is the moment when the diagnosis is made. Nobody likes to receive bad news and receiving a diagnosis, regardless of the disease, is always difficult. In some cases, the diagnosis comes to confirm what we have already suspected. In my own case, I need particular thanks to the neurologist who gave me the diagnosis with the greatest possible empathy. He really put himself in my position and was able to transmit the diagnosis with great clarity and took the time to provide all the needed information. This is how it should be, in every case and for every patient.

And this brings me to the first recommendation of our group: the diagnosis should be communicated to the patient and the doctor should address the patient directly to provide the information.

In addition, it is important how the diagnosis is being communicated. It should be done with plenty of time to allow the patient to ask questions. Once the diagnosis has been given to the patient, the doctor should also include, when possible, the family to ask questions. The communication should also be done in an accessible and easy-to-understand language and provide information on the disease, possible treatments, but also information on the local Alzheimer’s association. In my case, I wanted to highlight how important this was. I felt very down after the diagnosis, but the professionals I met at AFA RIOJA, my local association, were able to help me enjoy life again and also to make me want to collaborate so that others have the same opportunities that I received.

Our group discussed the importance of receiving a timely diagnosis and even of receiving information at the prodromal stage of the disease before dementia. Even without a curative treatment, I feel that it would allow a person and the family more time to prepare and to put their affairs in order. Our group also wishes to promote this timely diagnosis and sees this as an important development for the person and his/her family, but also for research.

This brings me to the subject of research. Although, I am not an expert in this field, I am aware that a great number of people is involved in research and looks into ways of curing, preventing, delaying or modifying the disease. It is also important to see that there are research efforts underway in basic, clinical and social research.

As a person with the disease, it is frustrating though to see that despite all these research efforts, we have had no new medicines. Also, we seem to be spending more money for research into hair loss than we spend on Alzheimer’s disease. I would therefore dare to make the recommendation that the different research teams need to coordinate better in order to truly exchange the knowledge that is being generated.

Personally, I would also like to volunteer to participate in a clinical trial, but for that to happen, I need to know whether there are trials, where they are, who is responsible for them and what the objectives of the trial are.

In Spain, we should improve this type of communication, as well as trial recruitment which should become more agile and efficient. I am sure, we would all gain from this. Wouldn’t it be great if we were the last generation of people affected by Alzheimer’s disease?

Wouldn’t it be great if we were the last generation of people affected by Alzheimer’s disease?”

Our Expert Panel also considers research to be important and wishes to support all types of research at the same level and recommends that we increase the budgets for research.

As we are hoping for progress from research, we also need to ensure that our health and social care sector is prepared for Alzheimer’s disease and for us, both sectors are equally important. The question of how to improve services would be worth its own contribution, I would therefore like to limit myself to promoting person centred care. Planning for services should therefore start from the rights of people in need of these services rather than from a purely economic and budgetary point of view.

When talking about rights, it is equally important to also think about employment. A diagnosis in itself should not be a reason to lose your job and to become “incapable” from one day to the next. Shouldn’t there be possibilities to adapt jobs, profiles and responsibilities to the capabilities of the person. Of course, this would have to be done on
a voluntary basis, but I can assure you that I would have liked to continue to work for the company to which I had dedicated a good part of my life. Again, our group feels that these employment questions need attention at a policy level and wishes to support the initiative of CEAFA to create more dementia-friendly companies.

Last but in no ways least, I want to discuss the family environment. A diagnosis does of course not only impact the person, but also the whole family and the needs of family carers have to be addressed supported. If people with dementia wish to remain who they are (“sigo siendo yo”), family members and carers also have that same right.

If I can make a recommendation to family carers, it is that they should think of giving some space to the person diagnosed, especially during the early stages of the disease where persons still have a lot of their capacities. This will make us feel valued and useful and will make us feel less of a burden.

I would have liked to continue to work for the company to which I had dedicated a good part of my life

My PEPA colleagues also recommend that family members should help to promote the autonomy of the person with dementia as far as possible and delay guardianship or “incapacitation” measures for as long as possible. Instead, empowerment should be something that should be actively encouraged.

These are some of the recommendations that our group developed and we really hope to see these implemented in the future Spanish National Alzheimer’s Plan. Our group actively contributed to the development of such a plan and we hope to see the launch of this important document very soon.
Research on Alzheimer’s disease and other dementias in Spain

Adolfo Toledano provides an overview of Alzheimer’s research in Spain from its historical beginnings to current day priorities.

Historical background

Spain has been very interested in Alzheimer’s disease and other dementias since Alois Alzheimer first announced his investigations in 1906. Many histopathologists, neurologists and psychiatrists have since devoted their efforts to understanding Alzheimer’s disease and its causes. The most important reference to the direct involvement of neurohistologists and neuropathologists comes from the school of Santiago Ramón y Cajal (a primary exponent of the new field of neuroscience which had received the Nobel Prize in 1906).

The study of alterations to the brain as a result of Alzheimer’s disease were of special importance owing to the novel use of a metallic staining technique utilised by Cajal and his contemporaries (including Lafora, Tello, Gayarre, Valverde, Del Río Hortega etc.). Of particular importance was the contribution of Nicolás Achúcarro, a researcher who carried out his doctoral thesis with Alois Alzheimer (1905–6) on rabies and later worked with him on brain neurodegeneration.

In 1908, Alzheimer was invited to lead Washington’s neuropathology laboratories in the USA (Government Hospital for the Insane) to develop his research on his “new disease”. He recommended Achúcarro for the position, who accepted and served for two years in the position. During this time, one of his main contributions was to identify the important role of glial cells in neurodegeneration, a factor which has been revisited and recognised as crucial in Alzheimer’s disease in recent years.

On his return to Spain, Achúcarro was recruited by Cajal for his laboratory, his chair in the Complutense University of Madrid and for the General Hospital of Madrid, where he created a department with laboratories of histopathology, neurology and psychiatry for the study of dementia. Unfortunately, Achúcarro died in 1918 aged 38, but not before leaving an important school in clinical and basic neuroscience for Alzheimer’s and related neurodegenerative diseases.

For several decades (1920–1960), Alzheimer’s disease did not receive significant attention until a social revolution took place in the US. But during these years, the dedication of professionals in psychiatric hospitals, such as the Ciempozuelos in Madrid and others scattered across Spain, governed largely by religious congregations, was relevant to patients with what was then commonly referred to as “senile dementia”.

The current situation of Spanish research on Alzheimer’s and other related dementias.

Since 1960, research into Alzheimer’s disease has increased exponentially all over the world and in Spain it has happened in parallel. At present, there is no prominent biomedical research centre, hospital or university which does not have high-level research units or laboratories, with research teams dedicated to the investigation of Alzheimer’s disease and other dementias in basic and clinical neurosciences.

There are large research groups in Spain that cover all areas of research: basic, clinical and social health fields. Basic research covers all aspects, from the research of Alzheimer’s neurodegeneration in human brains to research in animal models of Alzheimer’s disease.

Spain has a number of brain banks that collect samples of brain tissue (Madrid, Barcelona, Basque Country) for studies on Alzheimer’s and related diseases (vascular dementia, frontotemporal dementia, Creutzfeldt-Jakob disease etc.). These brain banks are connected to the European network of Brain Banks, most of which are also linked to epidemiological research projects which analyse the development of various types of dementia and neurodegenerative diseases. One example of this is the Reina Sofía Centre and its Vallecas project which carries out an epidemiological follow-up of a population in central Spain, looking for any relationship with dementia and examining people from 65 years of age, through to possible development of dementia, through to post-mortem analysis after death.

Nicolás Achúcarro (A) in the Santiago Ramón y Cajal (C) research team
In large hospitals, highly relevant clinical studies focusing on different aspects of social health are carried out, including early diagnosis, clinical follow-up, pharmacological and non-pharmacological treatment. In addition, studies examine genetic determinants, analysis of blood and cerebrospinal fluid markers (which assist with diagnosis and developing knowledge of pathology) and the use of neuroimaging. Furthermore, studies are carried out to detect pre-dementia pathological states, mild cognitive impairment and other pre-dementia situations and mixed Alzheimer’s dementias, as well as comorbidity with other conditions such as Type-II diabetes.

In genetic studies, great advances have been made in relation to the importance of the APOE-4 gene, as well as complex studies on several groups of genes (more than 1,000) that indicate different functional groups of global alterations (neurodegenerative, vascular, metabolic etc.) that are associated with dementia.

Overall, the analysis of high-impact publications (for example, Medline) show that publications produced in Spain in almost all fields of research on Alzheimer’s disease research are of considerable interest in the field, with more than 11,000 citations in the last 10 years.

Most of the major centres and research teams develop coordinated programmes among themselves, as well as with various foreign centres, especially European centres, including the Joint Programme of the European Union for Research in Neurodegenerative Diseases. Additionally, several Spanish research consortia (including the CIBERNED network of research centres, which involves universities, hospitals, state research centres and the Reina Sofía Alzheimer Reference Centre) are integrated into the worldwide network of Centres of Research Excellence in Alzheimer’s, with more than 900 researchers participating since 2012. These teams are also present in more than 50 European research projects.

Collaboration with Alzheimer’s associations

Spanish research on Alzheimer’s disease operates in a collaborative manner to analyse all the pathways for the development of dementia to prevent the disease and to help patients and families.

It is therefore helpful to recognise the importance of Alzheimer’s associations such as Fundación Alzheimer España (FAE) and CEEAF that have collaborated to ensure that patients and families can participate in these studies. It is also useful to highlight that FAE is committed within its statutes not only to providing training, information and assistance to families, but also to promoting research on Alzheimer’s disease and dementias.

These associations and other foundations (such as the ACE-Barcelona, CITA-Basque Country, Maria Wolf-Madrid, etc.) collaborate especially in the development of new forms of comprehensive care for people with dementia, support for families and the implementation of new non-pharmacological methods, technologies and non-hospital based forms of care. They also collaborate with clinical research, encouraging the participation of patients and their families in clinical trials, research technologies and epidemiological studies.

Although Spain does not yet have an officially approved National Alzheimer’s Plan (which FAE and other organisations have called for for more than 30 years), it is apparent that some government actions indicate an increase in research in all areas related to Alzheimer’s and other neurodegenerative diseases. This is reflected in the already approved “Strategy against Neurodegenerative diseases” (Ministry of Health, 2016) and the future “National Alzheimer Plan”.

Considering the research agenda as a whole, it is necessary to develop a joint programme to achieve greater efficacy in translating our knowledge and findings of dementia and associated diseases to facilitate diagnosis, prevention and treatment of dementias, as has taken place in other European countries. The cohesion and coordination of all research projects throughout Spain and the rest of the world is a goal that must be achieved to take the definitive step to overcome dementia, as well as increasing funding for research and development, both public and private, as well as intensifying the training of researchers in neurosciences and clinical physicians who will become future experts in mental disorders.

Profile

Dr Adolfo Toledano is a Board member (Patrono) of Fundación Alzheimer España and a Chief Investigator at the Cajal Institute at the Spanish National Research Council (Consejo Superior de Investigaciones Científicas, CSIC).

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Barcelona, a city of excellence for Alzheimer’s disease research

José Luis Molinuevo and Carolina Minguillón from the Barcelonaβeta Brain Research Center and the Pasqual Maragall Foundation present Barcelona as a vibrant centre for research in the field of Alzheimer’s disease.

Barcelona, the host city of the 28th Alzheimer Europe Conference “Making dementia a European priority”, is a hub for Alzheimer’s disease (AD) research in Europe. With a thriving multidisciplinary research community investigating all aspects of AD from basic understanding of disease pathophysiology to engagement of patients and carers, Barcelona is on the front line of the fight against Alzheimer’s. Here, we give an overview of the main centres in Barcelona partnering in European consortia focused on AD.

Barcelonaβeta Brain Research Center

The Barcelonaβeta Brain Research Center (BBRC; www.barcelonabeta.org), founded in 2013 and led by Dr José Luis Molinuevo, M.D., is the research institute where the Pasqual Maragall Foundation (fpmaragall.org) carries out all its scientific activities and is dedicated to research on AD prevention.

BBRC has a multidisciplinary research team composed of neurologists, neuropsychologists, nurses, biologists, engineers, physicists and computer scientists that bring expertise in AD pathophysiology, genetics, biomarkers, and neuropsychological evaluation, as well as the acquisition, analysis and processing of neuroimaging data (Magnetic Resonance Imaging [MRI] and Positron Emission Tomography [PET]).

Research at BBRC is possible thanks to the altruistic implication of ~3,000 cognitively healthy persons (most of them first-degree descendants of AD patients, aged between 45 and 74 years) that participate in the ALFA (for Alzheimer and Families) project. ALFA participants are thoroughly characterised from a sociodemographic, clinical, genetic, lifestyle and cognitive perspective.

The ALFA project represents a valuable cohort of middle aged participants representing the whole spectrum of risk that leverages with different AD prevention studies and trials. The ALFA+ study is a nested longitudinal cohort that includes 450 participants which undergo repeated, every 3 years, wet (CSF and blood sample collection) and imaging (MRI, amyloid and FDG PET) biomarker analyses. This information will serve to untangle the natural history of the disease and model the preclinical stages, aiding the development of successful trials.

Aside from BBRC-sponsored studies and industry-sponsored prevention clinical trials, the ALFA study is aligned with European initiatives that are summarised here. BBRC co-leads the European Prevention of Alzheimer’s Dementia (EPAD) study, a collaborative research project with the main purpose of developing the infrastructure for performing proof of concept trials for the prevention of AD dementia.

For this purpose, from a single pan-European EPAD registry, participants are invited to join the EPAD longitudinal cohort. From this cohort, selected participants will be invited to join in the EPAD “adaptive” trial for developing drugs designed to prevent Alzheimer’s dementia. The “adaptive” trial design should deliver better results faster and at lower cost. EPAD is funded by the Innovative Medicines Initiative (IMI), an association between the European Union and the European Federation of Pharmaceutical Industries and Associations (EFPIA) (see pages 16–17 for an update on EPAD’s latest achievements).

BBRC also participates in the IMI2-funded Amyloid Imaging for the Prevention of Alzheimer’s Disease (AMYPAD) project. AMYPAD is the largest collaborative project carried out in Europe with the aim of improving the understanding, diagnosis and treatment of AD through β-amyloid PET imaging. AMYPAD will study the utility of β-amyloid PET imaging to 1) impact the clinical workup of persons suspected to have Alzheimer’s, 2) to study the natural history of amyloid accumulation in the preclinical phase and 3) to improve the selection of subjects for inclusion in prevention trials. BBRC co-leads AMYPAD work package 2, which deals with tracer delivery, scan acquisition, quality control, transfer, quantification and, ultimately, sharing of image data across the study.

The final IMI-funded project in which BBRC participates is AETIONOMY, which was established to respond to the need to re-classify diseases according to mechanisms that contribute to disease aetiology at the molecular (“omics-”) level rather than the current phenotypic approach. The scientific community believes that a coordinated effort is necessary to transform drug development and medicine by incorporating the advances in the understanding of molecular and genomic variation of a disease into its diagnosis and treatment.

It is finally worth mentioning that ALFA has recently joined forces with a similar UK-based cohort (PREVENT) to establish TriBEKa (www.tribeka.org/), a consortium aimed at understanding the specific brain changes that take place during middle age. To achieve this, an open-access neuroimaging platform will be generated to help understand the changes that occur in the brain up to 20 years prior to the appearance of the first symptoms. The platform will obtain data from over 1,000 healthy participants of between 40 and 65 years of age, from the prevention cohorts of different centres: ALFA in Spain, PREVENT in the UK, and FINGER in Finland. All the information collected in the project will be shared to respond to the need to re-classify diseases according to mechanisms that contribute to disease aetiology at the molecular (“omics-”) level rather than the current phenotypic approach. The scientific community believes that a coordinated effort is necessary to transform drug development and medicine by incorporating the advances in the understanding of molecular and genomic variation of a disease into its diagnosis and treatment.

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available to the global scientific community, through the data exchange platform known as Global Alzheimer’s Association Interactive Network (GAAIN). The consortium is funded by the Alzheimer’s Association and an international anonymous charity foundation.

Hospital Clinic of Barcelona

The Alzheimer’s Disease and other Cognitive Disorders Unit (ADCD) at the Hospital Clinic of Barcelona (www.hospitalclinic.org), linked to the Institut d’Investigacions Biomèdiques Augustí Pi i Sunyer (IDIBAPS) and the University of Barcelona, is a multidisciplinary clinical and translational group of 20 professionals. Led by Dr Raquel Sánchez-Valle, MD, it is focused on the diagnosis, management and research of neurodegenerative cognitive disorders.

ADCD participates in neuropathological studies in neurodegenerative dementias in collaboration with the Neurological Tissue Bank at the same centre (www.clinicbiobanc.org) and BrainNet Europe. ADCD participates in several international projects and/or consortia funded by international or EU agencies. The Dominant Inherited Alzheimer’s Network (DIAN) that aims to characterise, design and manage interventional therapeutic trials for individuals with and at risk of autosomal dominant AD; the Genetic Frontotemporal dementia Initiative (GENFI) and the EU Joint Program JPND PreFrontALS that studies genetic Frontotemporal dementia (FTD); the EU-Early onset dementia consortium, focused on the study of genetic markers and causes of early onset dementia; the EU EIT-Health AD Prediction Service that evaluates the accuracy and performance of a prototype app that tracks gamified daily routines in order to estimate at an individual level the risk of cognitive worsening in subsequent years; the IMI-AETIONOMY (see above).

Finally, in collaboration with BBRC, the H2020 Medit-Aging investigates the potential of meditation to promote mental health and wellbeing in the ageing population and prevent AD; the EU Joint Program EURO-SCD with the objective to create a transnational, harmonized definition and assessment protocol of subjective decline for early intervention trials.

Sant Pau Memory Unit

The Sant Pau Memory Unit (www.santpaumemoryunit.com) at the Hospital de Sant Pau is a multidisciplinary group of 35 professionals led by Alberto Lleó, M.D. The Unit is composed of neurologists, neuropsychologists, nurses, biologists, engineers and lab technicians devoted to medical care and translational research in the field of dementia. The Unit offers highly specialised medical care and clinical trials to patients with AD and other dementias, such as FTD and dementia with Lewy bodies (DLB).

The Unit has a specific programme for the detection of AD in Down syndrome (DS). The Unit combines clinical care with clinical and translational research activities. Recently, the Unit has launched two large research cohorts: The SPIN (Sant Pau Initiative in Neurodegenerative diseases) cohort for biomarker discovery and validation in AD, FTD and DLB, and DABNI (Down Barcelona Neuroimaging Initiative) for characterisation of AD biomarkers in DS.
In addition to several national studies, the Unit has been actively involved in several European and international projects, such as EADB (European Alzheimer’s Disease DNA Bank) aimed at disentangling the genetic basis of AD through the generation of GWAS-based population data; the EOAD (EU-Early onset dementia) which investigates the genetic causes of early-onset AD; T21 Genetic Consortium, which focuses on DS genetics; and the BIOMARKAPD, which investigated harmonization protocols for CSF biomarkers. The Unit receives funding from national and international agencies including the Alzheimer’s Association, Jêrome-Lejeune Foundation, Michael J Fox Foundation and the National Institute of Health.

The initial Alzheimer’s Education Center established in 1991 has evolved based on the changing needs and demands of patients and their families, and also based on the novel evidence-based therapies and management techniques. The clinical database of Fundació ACE contains more than 23,000 clinical records and new data from approximately 1,700 new patients are added every year. This database also contains important longitudinal clinical data and has been open to accredited researchers worldwide since 2014 (GAAIN initiative).

ACE research encompasses diverse fields such as genomics, genome-wide association studies, molecular epidemiology, phenomics, biomarkers, neuroimaging, social legal and ethical research, robotics, and brain training. ACE participates as a partner in numerous national and international projects or collaborations. It is a member of the Cohorts for Heart and Aging Research in Genomic Epidemiology (CHARGE) consortium, the International Genomics of Alzheimer’s Project (IGAP) consortium, the European Alzheimer Disease Consortium (EADC), the European Lewy Body Disease consortium (eDLB), the European Early-Onset Dementia consortium (euEAD) and the Alzheimer’s Disease Neuroimaging Initiative (ADNI), among others.

In summary, it is clear that Barcelona is truly a hub of excellence for Alzheimer’s research thanks to a critical mass of investigators and healthcare professionals in diverse fields such as medicine, biology, psychology, engineering and social care. The above described four research centres keep on developing partnership to increase their degree of collaboration and alignment. It should be emphasised that without the engaged participation of thousands of persons from Barcelona and surrounding areas the studies summarised here would not be possible. The honour of hosting of the 28th Alzheimer Europe Conference “Making dementia a European priority” will only serve to further the potential for future collaborative projects with our European colleagues.
Our members are helping people with dementia and their carers in 35 countries.

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