Sirpa Pietikäinen MEP signs the #DementiaPledge2019 and becomes Chairperson of the European Alzheimer’s Alliance

Alejandro Moledo talks about the European Disability Forum’s campaign for equal voting rights

Jayne Goodrick receives a “Points of Light” award for her advocacy work for people with dementia and carers

Petri Lampinen shares his thoughts on the new European Disability Card
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by Iva Holmerová, Chairperson of Alzheimer Europe

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Contact
It is with great pleasure that I welcome you to the 30th edition of our Dementia in Europe magazine.

The first section gives an overview of some of the work in which Alzheimer Europe has been involved, including our work on three different research projects (RADAR-AD, PARADIGM and AETIONOMY). We also provide a look into how we approached the European Parliament elections and an introduction to the new members of the European Working Group of People with Dementia (EWGPWD). I would like to thank them for their involvement in our election campaign, without which we would not have been so successful in getting MEP candidates to commit to making dementia a priority.

We also take a look back to February 2019 at our lunch debate in the European Parliament which focused on dementia research as a European priority. Attendees heard presentations from Pierre Meulien of the Innovative Medicines Initiative (IMI), setting out how the partnership had supported dementia research; Mikko Hiltunen of the University of Eastern Finland, who shared some of the work being done in relation to the genetics of dementia; and from Stéphane Hogan of the European Commission, who detailed how the Commission had provided resources and a strong framework to support dementia research in Europe. I would like to thank Sirpa Pietikäinen MEP (Finland) for organising the meeting; Anneli Jätteenmäki MEP for chairing the debate itself; Heinz K. Becker MEP (Austria) who participated; and also Martina Anderson MEP (UK, Northern Ireland) who was represented at the meeting.

We have an interesting article from the European Disability Forum which has shared how it approached the elections, campaigning against barriers, both legal and physical, which prevent or restrict persons with disabilities from voting across Europe. Additionally, we are pleased to have a contribution from colleagues Dan Chisholm and Katrin Seeher, from WHO Europe and the World Health Organization respectively. They focus on the progress and future work on the Global Action Plan for Dementia.

We then examine the most recent developments in relation to a significant policy area for dementia research, Horizon Europe, before briefly providing an overview of the latest Brexit developments and their implications for different aspects of European policy and practice. We conclude this section on a positive note, with the announcement by the Spanish Government, which has provided an outline of the main areas of focus for its forthcoming National Alzheimer’s Plan.

Our Dementia In Society section covers a range of policy-related activities in which our members have recently been engaged. Our Finnish colleagues have been busy in a number of areas, with Muistiliitto (The Alzheimer Society of Finland) organising the country’s first ever “Memory Friendly Parliament”, at which people with dementia and carers were able to ask MPS questions. Additionally, Finnish EWGPWD member Petri Lampinen has shared with us his experience of using the new European Disability Card.

It has also been an active time for different carers’ networks across Europe, with networks across the UK, Ireland and Portugal working on various projects to improve the experience of carers of people with dementia. So effective has this been in Wales, that Jayne Goodrick (who supports EWGPWD member Chris Roberts) has received an award recognising her tireless campaigning work in ensuring the voices of carers are heard. I warmly congratulate her on this great achievement. Having been a carer myself, I know how hard it is. I am so impressed with the work that these carers’ networks, and the individuals that belong to them, are doing.

Our French colleagues have been continuing their campaign against the decision of the French Government to stop reimbursing dementia medication. France Alzheimer President Joël Jaouen tells us about a recent survey showing the hugely negative impact this 2018 decision has already had on people with dementia and their families across the country.

Concluding this edition of the magazine, Jim Pearson from Alzheimer Scotland talks to us through their campaign on care charging for people with advanced dementia, following the publication of a report by a dedicated commission examining the issue.

I would like to wish you all the very best for the summer and look forward to welcoming you for our next edition in October in which we will be previewing our annual conference, which will take place in The Hague, Netherlands, between 23 and 25 October 2019.

Happy reading!
European Parliament lunch debate focuses on dementia as a European research priority

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

Alzheimer Europe (AE) held its first lunch debate of 2019 in the European Parliament on 26 February 2019, focusing on dementia as a European research priority.

Hosted by Anneli Jäätteenmäki MEP (Finland) (standing in for Sirpa Pietikäinen MEP), the debate was attended by 64 delegates from across Europe, including the Chair of the European Working Group of People with Dementia (EWGPWD), national Alzheimer’s associations, research partners, pharmaceutical representatives and members of the European Parliament.

The Innovative Medicines Initiatives (IMI)

The Executive Director of the Innovative Medicines Initiative (IMI), Pierre Meulien, presented on the work of IMI through both its iterations, IMI1 (2008–2013) and IMI2 (2014–2020), highlighting that the public-private model of funding had yielded over EUR 5 billion investment, with over EUR 300 million invested in brain disorders and over EUR 200 million invested in drug discovery to date.

Dr Meulien identified a shift in approach towards molecular mechanisms, acknowledging that the previous focus on disease-modification in the symptomatic stages of neurological conditions, including dementia, had not been effective. As such, the overarching approach to neurodegenerative conditions focused on four key areas: underlying causes, populations at greatest risk, improved clinical trial design and brain scanning as a means to improve detection and treatment. Examples of IMI-funded research projects underway included the “European Prevention of Alzheimer’s Disease” (EPAD) and “Amyloid Imaging to Prevent Alzheimer’s Disease” (AMYPAD) projects.

Dr Meulien explored the value of health data projects as a means of improving healthcare systems and delivering better outcomes for patients, including through the use of emerging smart technology. “Big Data for Better Outcomes” (BD4BO) was highlighted as an example of such an approach, with the project aiming to improve sustainability within healthcare systems. “Real world Outcomes across the Alzheimer’s Disease spectrum for better care: Multi-modal data Access Platform” (ROADMAP) project sat under this umbrella.

Research in Finland

Mikka Hiltunen, Professor of Tissue and Cell Biology at the Institute of Biomedicine, University of Eastern Finland (UEF), presented on current research being carried out within his institute concerning brain health in the older population, with a specific focus on biomarkers as a means of prevention and early detection for dementia. Prof. Hiltunen explained that understanding the genetics of Alzheimer’s disease was one of the best ways to improve knowledge on the condition.

“Dementia affects the daily lives and routines of millions of people and their family members, friends and carers. Research is the key to fighting dementia.”

Anneli Jäätteenmäki MEP

“The public-private partnership model is the ideal vehicle to drive technological convergence enabling more robust health systems and better practices in health promotion, disease prevention and management.”

Pierre Meulien
Expanding on this, he described the work of Neurocenter Finland, which works to integrate neuroscience research into disease prevention, diagnostics, treatment and rehabilitation, as well as promoting collaboration and research innovation.

He also provided an overview of the AlzTrans project was provided, which seeks to evaluate the translational aspects, feasibility and applicability of novel Alzheimer disease-associated risk genes/variants, as well as Finland’s involvement in international research collaborations. The overview included reference to the EU’s Joint Programme on Neurological Diseases (JPND), which involved the European DNA Bank for deciphering the missing heritability of Alzheimer’s disease, which collated ~40,000 patients and ~66,000 controls from 13 countries.

Finally, Prof. Hiltunen outlined a further example of Finnish collaboration with other EU research programmes, through the work of the “Genetics and Mechanisms in Translational Medicine Doctoral Programme” (GenomMed), which will train specialists in translational genomics to solve health care-related questions in the fields of neurosciences, cardiovascular and metabolic diseases.

“\nIt is paramount to continue developing collaboration and platforms for researchers in the field of neurodegenerative diseases – thus, Neurocenter Finland is coded to connect researchers and other stakeholders.”

Mikka Hiltunen

European Commission funding for research

Stéphane Hogan, Head of Sector for Neuroscience in the Directorate General Research and Innovation at the European Commission, highlighting the EU’s support for dementia research in Europe. Mr Hogan, outlined that the EU’s contribution across frontier research, collaborative research and training and mobility had totalled EUR 664 million, with EUR 339 million going towards projects on, or involving Alzheimer’s disease.

“It is paramount to scrutinise the highly individual cultural and political factors influencing the lives of people with dementia, taking into consideration the similarities and differences across but also within Europe.”

Iva Holmerová
Mr Hogan provided an overview of the approach of the European Commission across six areas, including molecular pathogenesis, epidemiology, prevention, diagnosis and monitoring, treatment, and care and support. He drew attention to a number of projects across these areas, including the “Organising Knowledge about Neurodegenerative Disease Mechanisms for the Improvement of Drug Development and Therapy” (AETIONOMY) and “Prevention of Dementia using Mobile phone Applications” (PRODEMOS) projects, as well as partnerships such as JPND and IMI.

In addition to being a major funder of research, Mr Hogan noted that the role of the EU included providing a network of collaborative projects, as well as providing a framework for efficient research coordination between EU countries. When concluding, he outlined the approach of the forthcoming Horizon Europe programme, including its novel aspects such as dedicated research missions and a commitment to open science.

Alzheimer Europe publications launched

AE Chairperson, Prof. Iva Holmerová, thanked the speakers, MEPs and attendees for taking part in the lunch debate and officially launched two reports by Alzheimer Europe. The first, “The development of intercultural care and support for people with dementia from minority groups”, was the result of an extended piece of work undertaken with the support of partners across Europe, exploring how dementia was experienced by minority communities. The report highlights the need for specific considerations in relation to cultural differences in the understanding, status and position of dementia, which increase the stigma associated with the condition.

The second report, the Dementia in Europe Yearbook 2018, provides a comparison of national dementia strategies across Europe, comparing the content and policy priorities set out in each document. The report highlights the strong focus on systems of care and support for people with dementia, whilst also noting the frequency of other areas, such as research, training for professionals and awareness raising.

Open floor discussion

The session was concluded by an open floor discussion, with questions put to the speakers on a range of themes, as well attendees raising other points on other relevant issues.

Răzvan Prisada, the Romanian Health Attaché, attended the meeting, asking speakers about the high failure rate in relation to drug development for dementia and about timescales for the next significant breakthrough in dementia research.

Alzheimer Europe Executive Director, Jean Georges, asked about future research missions within the Horizon Europe project, noting the absence of a specific mission on dementia research. Iva Holmerová asked about the potential for greater involvement of Central and Eastern European countries in Horizon Europe research projects.

Helen Rochford-Brennan, Chairperson of the European Working Group of People with Dementia (EWGPWD), highlighted that as no cure was likely in the immediate future, more support should be given for programmes exploring psychological supports which ensure that people with dementia are able to live well with the condition.

Andy Bolan from Biogen expressed support for the work and connections made so far through IMI and queried how the work from the projects was being communicated in order to inform future partnerships, such as a potential IMI 3. Similarly, Gill Farrar of the European Federation of Pharmaceutical Industries and Associations (EFPIA), asked whether there was a specific piece of work bringing together the findings and work from current IMI projects.

Alzheimer Europe’s next European Parliament lunch debate will not take place until December 2019 owing to the European Parliament elections.
Snapshots from Alzheimer Europe’s European Parliament lunch debate

Helen Rochford-Brennan and Ana Diaz

Attendees arrive for the lunch debate

Alzheimer Europe’s reports were given to attendees

Heinz Becker MEP (Austria)

Jean Georges asks a question on Horizon Europe’s “missions”

Attendees listened to presentations on European dementia research

Former AE Chairperson Heike von Lützau-Hohlbein

Members catch up during the lunch debate

Attendees had the opportunity to network

Attendees had the chance to talk with presenters

Carmel Geoghegan speaks with Pat McLoughlin

Members discussed dementia research following the meeting
The RADAR-AD (Remote Assessment of Disease and Relapse in Alzheimer’s disease) project kicked-off in January 2019. The partners give an overview of the project’s aims and discuss how it plans to involve people with dementia in its research.

RADAR-AD is a collaborative research initiative that explores the potential of mobile and digital technologies to improve the assessment of Alzheimer’s disease (AD). The AD terminology in the RADAR-AD project reflects the recent conceptualisation of AD as covering the full spectrum of the disease, including both pre-dementia (preclinical and prodromal AD) and dementia phases (mild to severe AD dementia).

Why is ‘function’ relevant to AD?

When assessing the clinical symptoms of prodromal AD and mild AD dementia, the focus is typically on measures of cognition, such as memory tests, executive function and language. Although this can tell us how well someone’s brain is functioning on the day of assessment, it neglects to consider how AD impacts day-to-day living for affected individuals and their caregivers. There are certain tasks we need to do on a daily basis, often on multiple occasions in the same day, in order to function and meet our needs, such as getting dressed or preparing a meal. These repeated tasks vary in complexity, from walking or tidying up, to driving or managing finances. Such activities of daily living can become increasingly challenging, stressful and even hazardous for a person with prodromal AD or mild AD dementia.

As well as our ability to perform daily tasks, the ability to function within the social environment is important. This is particularly relevant because loneliness and social isolation are more common and have negative effects on health for older people and people with dementia. Social interactions often involve complex brain activity because both cognitive and emotional brain functions are employed, such as conversing or understanding non-verbal communication (e.g. body language and facial expressions). Measuring daily functioning is therefore important but has traditionally relied on questionnaires, rather than monitoring someone in their home or social setting.

RADAR-AD will look at how to use technology to capture reductions in the ability to function independently during activities of daily living or when interacting with others.

Incorporating the views of people affected by AD and their caregivers is vital to the success of RADAR-AD. Their insights will ensure that the ‘functional domains’ targeted for this study are:

- Appropriate and clinically relevant to affected individuals and caregivers
- Suitable for being recorded by digital devices
- Sensitive to the early stages of AD
- Able to predict AD progression.

Using technology in assessing and monitoring function in AD – some challenges in selecting devices

When assessing the level of difficulty and functional changes in daily living, researchers usually rely on feedback from family caregivers. This assessment may be influenced by subjectivity, inaccurate recall and, thus, it may not be reliable to estimate the level of impairment in affected individuals. This lack of objective data could be mitigated following recent advances in digital technology, which is why RADAR-AD is seeking to use widely available, affordable digital technology to try to improve current measures of function in AD.

For example, smartphones, currently owned by 9 out of 10 people, may help assess social
behaviour (e.g. via monitoring calls, SMS, or internet browsing). With the additional use of wearable wristwatches or wristband sensors, it may also be possible to measure activity level, stress level, heart rate, gait and other important information relating to daily functioning for people with dementia. Leveraging clinical and technological advancements to better monitor day-to-day functioning in AD, could lead to transformative management/treatment of this multifaceted and potentially disabling condition.

Incorporating the views of people affected by AD and their caregivers is vital to the success of RADAR-AD.

The number of different devices increases every year, resulting in a multitude of factors or parameters that developers need to consider, such as data heterogeneity, manufacturer standards and programming interfaces. End-users themselves also need to consider a range of factors such as shape, materials, battery life, design, functionality, precision and range.

All these parameters should be taken into account when selecting appropriate devices for monitoring users, especially when it involves people with AD dementia. Feedback from people with dementia, as well as their caregivers, introduces a most welcome end-user perspective in the selection process, highlighting parameters that might otherwise be overlooked by researchers.

Technology experts tend to select devices based solely on their desire to record the most appropriate signals with the highest granularity and precision, failing to take into account, for example, that the chosen devices might be uncomfortable, heavy or too complicated for study participants, resulting in projects which may be doomed to fail.

The selection of devices should not be made without the participation of patients themselves and, where appropriate, their caregivers. They could draw attention to how particular features might be tailored to fit their experiences of the disease, memory problems and other functional impairments, e.g. the need for a waterproof device, or for a sound or blinking light to remind users to charge the device. An optimisation process could then seek to identify the best compromise between the most technologically advanced devices and those most acceptable to users, thus satisfying both parties.

The RADAR-AD clinical study

To determine the potential and value of using these devices to assess and monitor function in AD, the RADAR-AD team will carry out an observational clinical study. The study will provide support to seamless digital measurements that have been identified as potentially useful in assessing functioning in people with AD. This clinical study will enrol people with a diagnosis of AD (based on a positive b-amyloid biomarker test). The study will look at the effectiveness of wearable and home-based digital sensors in detecting small changes in the performance of some activities of daily living.

The outcomes RADAR-AD are expecting to measure include social interaction, spatial navigation, outdoor mobility, driving and self-care. It is hoped this will provide more reliable information than questionnaires or diaries, which are currently used in clinical trials. 180 volunteers with a diagnosis of AD will be invited to take part in the study. They will include:

- people with preclinical AD (amyloid positive but no clinical symptoms),
- people with prodromal AD (some memory deficits but not dementia) and
- people with mild-to moderate AD dementia (with clinical signs of dementia).

In addition, information from 40 “healthy volunteers” (i.e. people with no AD) will be used to provide a comparison with people with AD of the same age. The study will last around eight weeks. During this time, each study participant will be requested to use wearable digital devices and answer questions on smartphones. A subgroup of 50 people with AD will also be monitored with digital technology installed in their homes, so as to profile behaviour at home.

The statistical analysis of results will provide information about which digital measurements most accurately predict the conversion to a different stage of AD and about how accurately they can detect the level of impairment in specific activities of daily living.

The study is planned to start in autumn 2019, at 13 different clinical centres of excellence located in 12 European countries, coordinated by the academic VU University Medical Center Amsterdam (VUMC) in Amsterdam and by the Pharma team of the Takeda Neuroscience Therapeutic Area Unit. Results are expected in approximately three years.

Patient involvement in the RADAR-AD project

Involving people living with AD, as well as those supporting them, is an essential part of the research trajectory in RADAR-AD. When following the progression of AD in a clinical setting, such as a doctor’s office, it is often difficult to capture real-life contexts. People living with AD can provide unique insights into daily life routines, how these may change over time and what practical issues researchers need to consider.

People living with AD play an important role as true partners to the RADAR-AD researchers. This is why a Patient Advisory Board (PAB) has been established, and will accompany the project from inception to completion. The PAB includes members from across Europe and advises on both conceptual questions as well as on practical issues, such as the trial setup. The PAB is led by Alzheimer Europe and will mainly include members of its European Working Group of People with Dementia (EWGPWD) and their supporters. During the meeting of the EWGPWD in March 2019 in
Luxembourg, members of the EWGPWD and their supporters were invited to provide input on various issues relevant to RADAR-AD. The group provided feedback on the definition and prioritisation of functional domains in AD and main features to consider when selecting a device for people with dementia. They also reviewed and provided advice on the protocol for the RADAR-AD clinical trial.

In addition to the PAB activities currently underway, similar discussions on relevant topics are being organised locally in the form of focus groups, which will be carried out in three different countries. This work is being led by King’s College London and the groups will involve people with prodromal AD, people with AD dementia and caregivers. Their input will build on the contribution of the PAB and may raise some additional issues and differences to consider.

“People living with AD can provide unique insights into daily life routines, how these may change over time and what practical issues researchers need to consider.”

Chris Roberts, member of the PAB and Vice-chair of the EWGPWD

Chris Roberts participated in the PAB meeting. He is from Wales and has a diagnosis of mixed dementia (Alzheimer’s and vascular dementia) but has not let this diagnosis get in the way of leading a full life. He said:

“As vice-chair of the EWGPWD, and also now member of the PAB, the RADAR-AD project looks very exciting and new. It aims to develop new ways of monitoring the progression and potential detection of early Alzheimer’s disease using wearable devices and smartphone technology. Nowadays, most people, including many people with AD, are using mobile phones and other technology, so it is great that this project will use this mobile technology to help record the progression of the disease rather than relying on sporadic tests and self-recording, which is often unreliable. An important strength of the project is that most of this data will be collected remotely and continuously, without interference in a person’s life. It is amazing to see experts from many fields, including medical research, engineering, computer science, information technology etc., working alongside people with AD and carers, to improve the quality of life of everyone affected by Alzheimer’s disease. On a personal point, I am really pleased to see that people living with Alzheimer’s disease will be involved.”

The RADAR-AD project has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n° 806999 and will run from 2019 till 2022.

www.radar-ad.org
@RADARAD7

www.imi.europa.eu
Why IMI PARADIGM?

Four stakeholders in the IMI PARADIGM project—Patients Active in Research and Dialogues for an Improved Generation of Medicines—tell us why they are committed to this initiative, what they hope will emerge from it, and why collaboration is key.

The IMI PARADIGM project is a public-private partnership co-led by the European Patients’ Forum (EPF) and the European Federation of Pharmaceutical Industries and Associations (EFPIA). The objective is to develop processes and tools for three key decision-making points: research priority setting, design of clinical trials and early dialogue. PARADIGM will integrate the needs, perspectives and expectations of all actors involved and produce a set of metrics to measure the impact of patient engagement.

**The patient perspective – Jean Georges, Executive Director, Alzheimer Europe**

Dementia affects around nine million people in Europe. Despite much effort, no treatment exists to date to cure, prevent or slow down its progression. Globally, and at European level, a lot of research is being conducted, which is helping to better understand what causes dementia, the risk factors, its progression, how to cope and live better with the condition and to develop more effective treatments and care options.

Examples of people with dementia and their carers being meaningfully involved in research do exist, but several challenges still need to be addressed, for example, existing misconceptions and stigma around dementia. People living with the condition should feel empowered, enabled and supported and should be afforded the opportunity to take part in and contribute towards research, if they so wish. They can play an important role as research participants and contribute their opinions about the type of research that they would like to see prioritised, how this research should be undertaken or how the findings should be disseminated to the dementia community and to the wider public.

At Alzheimer Europe, we have been pioneers in promoting the involvement of people with dementia in our own work and in research. A key objective of our strategic plan is to provide a voice to people with dementia and their carers, so that they can be full partners in policy development, research and service design. In 2012, inspired by the work that had been done in Scotland, we set up the European Working Group of People with Dementia (EWGPWD). Members of the EWGPWD and their supporters have provided important input to a number of prominent European projects, have contributed to published scientific articles and are helping to bring the voice of the experts by experience, “the lived experience”, to many discussions and debates around dementia research.

I am very proud of the work the EWGPWD carries out and of the work they are now doing in PARADIGM. I see Alzheimer Europe’s involvement in PARADIGM as a great opportunity to continue growing in this area—to improve the way we and our member associations around Europe involve people with dementia and to be able to demonstrate, in a concrete way, the important impact that experts by experience can make.

"PARADIGM is a great platform to imagine and advocate for different and better ways of engaging patients in research and medicines development. Let’s make the most of it!"

Jean Georges

**The industry perspective – Nathalie Moll, Director General, EFPIA**

At EFPIA, we work across a wide spectrum of topics from prevention and awareness, through research and development (R&D), regulatory and Health Technology Assessment (HTA) processes, managing relationships, to developing healthcare service design and outcomes measurement. Each one has a direct impact on the lives of patients, their families and carers across Europe.

Actively listening to patient experiences and patient challenges, and exchanging insights, must shape how we develop our policy, processes and practice. It is only through open and transparent dialogue between patients, industry and other key stakeholders that we can ensure the patient perspective becomes an integral part of how medicines are researched, developed and delivered to patients.

This is why patient engagement is at the forefront of EFPIA’s work and why I am very proud that EFPIA is part of the ground-breaking IMI PARADIGM programme. One of PARADIGM’s key strengths is its collaborative, inclusive approach, bringing together a wide range of stakeholders, including industry, the academic community, regulators and, most crucially, patients. PARADIGM has a specific focus on making patient engagement happen across three main moments of medicines development, where patient input is not yet systematically sought. We are sharing our knowledge and experience to develop new tools and processes and a sustainability roadmap and we hope to make a strong case for patient engagement by capturing and measuring the tangible benefits it brings.
PARADIGM’s ambition goes beyond providing practical tools and a measurement framework. This project is set out to bring real cultural change across the board, making collaboration an integral part of the European research culture, challenging the status quo and providing a safe space to discuss how to do things differently.

Cultural and practical change both take time and EFPIA and its PARADIGM partners are committed to making change happen to deliver better care for patients.

The research foundation perspective – Begonya Nafria, Patient Engagement in Research Coordinator, Fundació Sant Joan de Déu

Disease in minors can be considered as antinatural. A child is expected to be born and grow up healthy; nevertheless there are a huge number of conditions that have their onset in the early ages and only affect minors. This is especially so in the case of rare diseases. From the 8,000 conditions that can be considered rare, around 80% of them affect minors.

On the other hand, there are limited treatments available for paediatric patients and also an emerging need for medicines designed for children. 50% of treatments prescribed for paediatric patients have never been tested in this age group and when it comes to neonates this figure increases to around 90%.

The Paediatric Regulation that came into force in the EU on 26 January 2007, aimed to improve the health of children in Europe by facilitating the development and availability of medicines for children aged 0 to 17 years. Despite the regulation, however, more patient-centred research is required, in order to design better medicines for children.

Generally, minors have been considered vulnerable populations and, historically, have not been included in research projects. New approaches emphasise the need to conduct research for paediatric patients, including them in the early stages of drug development to ensure clinical trials are suitable for them. With this aim, the European Young Person’s Advisory Groups Network (eYPAGnet) was established in 2017 to provide a single point of contact in Europe to facilitate activities of patient and public involvement (PPI) in drug development, to answer the requests of the different stakeholders involved in the performance of clinical trials. Fundació Sant Joan de Déu is one of the founder members of eYPAGnet, and has a policy of including patients in all the research initiatives in which it is participating – from the evaluation of the call for projects, to the dissemination and communication of outcomes.

PARADIGM is a unique opportunity to standardise the involvement of vulnerable populations in drug development and also to design metrics to measure its impact. I envision a new landscape in future paediatric clinical trials, where patients will be stakeholders throughout the process. They will have a voice and contribute opinions to facilitate the development of projects according to their own needs. Thanks to the support of IMI, there is momentum for change to happen, to improve the landscape of medicines for children. Let’s do it together!

The academic perspective – Dr Stuart Faulkner, Programme and Operations manager, Nuffield Department of Primary Health Sciences, Oxford University

Patient engagement (PE) and patient and public involvement (PPI) can help develop research questions, methods and outcomes that respond better to the needs and interests of patients and carers. Researchers can benefit by producing research that is more relevant and impactful.

Many research funders increasingly require evidence of PPI/PE in research. There is a growing PPI ‘industry’ to support this: many academic institutions undertaking health research have designated PPI leads, strategies and plans in place, and much is said (and developed) about the need to ensure that best practice is followed. In addition, academic-industry partnerships are an increasing mainstay of the successful interface in the translation from ‘bench to bedside’ and embedded in the overarching strategies of academic institutions. Mechanisms to effectively integrate PPI into these partnerships are already being put in place, but more is needed.

Despite all this, the opportunities for academic groups to collaborate and co-create research with more than one other stakeholder group at a time are relatively rare, and often restricted to the local or regional levels.

PARADIGM is a unique opportunity to standardise the involvement of vulnerable populations in drug development and also to design metrics to measure its impact.”

Begonya Nafria

IMI PARADIGM offers unprecedented access to the expertise, experiences and perspectives of all of the major stakeholder groups involved in biomedical development and healthcare. This extends far beyond local levels and covers national, European and international territories. The platform of a public-private partnership opens up not only transparent dialogues between those stakeholders to answer the questions at hand, but can also break down long-seated barriers, misconceptions and myths of other stakeholder groups. The discourse is no longer split along the lines of ‘us’ and ‘them’. Problems are solved together as equal partners, working across pillars and helping to avoid silos and blinkered approaches to problems, often a criticism of some academic communities. Ideas and solutions are challenged at a level not possible with standard research approaches, and the solutions that are co-developed account for those differing options and needs of each stakeholder group much more readily.
Ultimately, the applicability, feasibility and impact of our combined work under PARADIGM is of much greater value to patients, the research community, and the broader stakeholder communities involved. Complementing this, is the increased level of public dissemination of our collective outputs – a much more readily digestible and accessible combination of openly available material – on a public platform containing multimedia outputs combined with traditional peer-reviewed scientific articles. The risk that research is understood by only a select few is greatly reduced.

Finally, the PARADIGM consortium sets the basis for growing strong and sustained relations with new partners and new stakeholders, which strengthens future collaborative potential, new research funding potential, and new mechanisms for knowledge brokerage. The partnerships and friendships already created here should last long into the future.

“We are Paradigm” – a campaign

The four stakeholder commentaries in this article are based on blog entries from a recent (April-May 2019) awareness and profile-raising social media campaign by the IMI PARADIGM project, #WeAreParadigm.

You can find the full blog texts on the project website: www.imi-paradigm.eu/blog

The platform of a public-private partnership opens up not only transparent dialogues between those stakeholders to answer the questions at hand, but can also break down long seated barriers, misconceptions and myths of other stakeholder groups. The discourse is no longer split along the lines of ‘us’ and ‘them’.”

Stuart Faulkner
AETIONOMY – towards a taxonomy for neurodegenerative diseases

The AETIONOMY project recently came to an end after five years. Dr Phil Scordis, Industry Coordinator for the project, explains its background and highlights some of its aims, as well as its outcomes. He also speaks to Academic co-lead Martin Hofmann-Apitius about the project's deliveries, approach and impact.

Despite many advances in modern medicine, today disease still tends to be defined based on the presentation of external signs and symptoms – a practice barely changed since the 19th century. Consequently, while two patients may share the same diagnosis, the underlying causes of their symptoms may be very different. Unfortunately, the result of this is that treatments that work for one individual may prove ineffective in another. Equally, while the development of an understanding of symptoms may be becoming more effective at directing physicians towards correct classification of disease, the lack of understanding of the drivers of disease keep us from developing effective treatments.

Innovations in certain fields of medicine, such as the treatment of oncology, have demonstrated that new models for disease classification are needed and, importantly, can be effective. These definitions, rather than being built on symptomatology, must be derived from the pathogenic mechanisms that drive the disease – the underlying molecular drivers.

An innovative and ambitious approach

The AETIONOMY project, started five years ago (2014) as part of the Innovative Medicines Initiative (IMI) Taxonomy call, has striven to pave the way towards an innovative approach to the classification of neurodegenerative diseases, focusing on Alzheimer's and Parkinson's diseases. During the project, the team aimed to address the classification of disease by dissecting the underlying mechanistic/molecular causes of disease, and by linking these to clinical evidence.

This ambitious goal was far beyond the scope of any single company, university or institution. The key to the success of AETIONOMY was the broad nature of the project consortium and the intense collaboration between project partners. Driven by a diverse group of scientists – the consortium comprised: clinicians with expertise in treating patients with neurodegenerative disorders; research scientists from several companies; and a group of data scientists – the project developed innovative computational tools to manage and interpret the complex healthcare and research data environment.

AETIONOMY's legacies

After 5 years of work, across a range of tasks, the legacies of the project are now clear.

Central to the project was the donation of samples from patients and control participants who generously participated in the clinical study, and the generation of new molecular insights from these samples. In addition, the result of significant effort to make available, to clean, associate and relate historical data that had been collated in various resources. The combined central knowledge base is now hosted in an environment that will support future researchers for many years to come: https://data.aetionomy.scai.fraunhofer.de/

These data have helped us verify computational predictions and explore a range of molecular theories underlying disease progression.

Ultimately, the project identified relationships between molecular drivers and a sub-grouping of patients that was evident in multiple independent datasets; as well as a grouping of features that might help predict the risk of rapid neurodegeneration in another sub-group of patients. These prototypical subgroupings represent hints at a mechanism-based taxonomy for neurodegeneration and a view of driver mechanisms underlying these disorders. We hope that this
will play a key role in drug discovery and development in both syndromes.

While these deliverables are certainly not treatment options for patients today, we believe they represent foundational building blocks that will support the community to move towards these goals. Indeed, only a few months after the end of the project in December 2018, the ongoing research across the original consortium members and new collaborative projects that have already started to extend the findings of the project, give us great hope for the future.

**Dr Phil Scordis, Industry Coordinator speaks to Martin Hofmann-Apitius, Academic Co-lead about the project’s key deliveries, its unique approach and its legacies**

**PS:** How would you describe the key deliveries of the AETIONOMY project?

**MH-A:** The approach of systematically capturing and representing knowledge on neurodegenerative diseases in a computable form (as a graph model that represents causes and effects and that can be analysed using algorithms that work on knowledge) and curate them, to re-annotate them and to aggregate them in a way that they can be used for modelling and mining. AETIONOMY has shown that this can be done in a difficult indication area (“neurodegeneration”). I believe we will see much more of such holistic approaches in the near future.

**PS:** On top of this effort to construct a comprehensive historical knowledge base, we have benefited greatly from the generosity of patients and volunteers donating samples and consenting to the use of these for the benefit of future research. With the clinical team, we have generated a comprehensive marriage between clinical observations and known molecular features in order to unravel disease aetiology. Now, I appreciate that it is early in the comprehensive analyses of these data, which we expect to fuel research initiatives for years to come, but can you say something about the exciting insights that may be emerging?

**MH-A:** The finding that a mechanism that has been predicted in silico (computationally) and links pathophysiology mechanisms involved in Alzheimer’s disease to pathophysiology mechanisms underlying Parkinson’s disease and that has a strong “stress sensor” component, has shown to be the strongest candidate for a subgroup-defining mechanism in Parkinson’s disease. We have not yet independently validated this pattern but it shows up in two independent Parkinson’s cohorts.

**PS:** What do you think this means for the future of research in Neurodegenerative Disorders?

**MH-A:** AETIONOMY was all about a systematic approach towards an entire indication area and this systematic ordering and analysis of data and knowledge is now being much more appreciated by the pharmaceutical industry.

**PS:** Indeed, the concepts that we explored in the beginning of the project may have been unusual in the NDD field but there is a groundswell acceptance in the biomedical community of the value of building the kind of integrated knowledge bases and the value of modelling and simulation to help us bring more and more clarity to the challenges of medical research and disease treatment development.

The research leading to these results has received support from the Innovative Medicines Initiative Joint Undertaking under grant agreement n°115568, 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.

[www.aetionomy.eu](http://www.aetionomy.eu)
Looking back at Alzheimer Europe’s #DementiaPledge2019 campaign

In the run up to the European Parliament elections, Alzheimer Europe worked with its members to run a campaign, asking candidates in the election to sign up to its pledge to make dementia a European priority.

In this article, we look back at the activity over the course of the past few months, leading up to the European Parliament elections, including the pledge itself, social media activity in relation to the pledge and how our members helped us build a successful campaign.

A separate article on page 21 provides a post-election analysis of the European Elections, including the number of candidates who signed the pledge and the numbers of members within the European Alzheimer’s Alliance (EAA), as well as a brief timeline of the next steps in the political process, and what this means for Alzheimer Europe’s policy activities.

The #DementiaPledge2019

Alzheimer Europe launched its campaign for the European Parliament election 2019, at its Public Affairs meeting in on 27 February 2019, asking our members to join us in asking candidates standing for election to commit to making dementia a European priority.

As with the 2014 election, Alzheimer Europe produced a “Dementia Pledge”, asking candidates to work with us, if elected to the European Parliament, to make dementia a European priority by joining the EAA, prioritising dementia in a number of policy areas and participating in dementia friendly initiatives in their countries.

In order to increase the likelihood of candidates signing the pledge, we wanted to ensure that it was available in as many languages as possible. Through the support of our members, the pledge was available in 15 different languages:

- Bulgarian
- Croatian
- Czech
- English
- Finnish
- French
- German
- Greek
- Hungarian
- Italian
- Luxembourgish
- Polish
- Slovenian
- Spanish
- Swedish.

Showing the support of candidates

Alzheimer Europe wrote to all 751 existing Members of the European Parliament (MEPs), asking them to sign up to the election pledge. Additionally, we contacted all members of the EAA asking them to pledge their support.

For the first time, Alzheimer Europe allowed candidates to declare their support for the pledge in a number of ways, not solely by completing and returning the pledge form. Candidates were able to indicate their support through social media (primarily through Facebook or Twitter) by including the #DementiaPledge2019 hashtag, as well as by directly replying to the emails sent them.

All responses and candidates’ messages of support were recorded on a spreadsheet, including noting the national and European party affiliation, where support had been indicated, and (for existing MEPs) their EAA status. Doing so allowed us to gauge progress on the campaign, identifying the distribution of support across countries, as well as making it easier to identify supporters post-election.

To increase visibility for the campaign, Alzheimer Europe thanked all candidates for their support for the pledge on Twitter, whilst also uploading the names of signatories onto our website.

Involving the European Working Group of People with Dementia

Alzheimer Europe was delighted to be able to involve the European Working Group of People with Dementia (EWGPWD) as a part of the campaign, ensuring their voices were heard by candidates.

Members of the group were asked about their views on why MEPs should sign up to the pledge and the issues they wanted to see MEPs focus on should they be elected. Five members of the group contributed messages:

- Helen Rochford-Brennan (Ireland)
- Idalina Aguiar (Portugal)
- Petri Lampinen (Finland)
- Stefan Eriksson (Sweden)
- Chris Roberts (UK - Wales).
From this, we were able to make a number of images in English, which were shared with our national associations, as well as used by us both on our website and on our social media platforms. Additionally, the graphics we created for Idalina and Petri were also made in Portuguese and Finnish to provide a resource which was more likely to engage candidates in their countries.

**Approach of our members**

The effort of Alzheimer Europe’s members in gathering the support of candidates for the campaign was vitally important, particularly as being approached by a national organisation creates a greater imperative for candidates to recognise dementia as a priority.

Our members worked in different ways to gather signatures, creating and adapting resources to encourage candidates to sign-up. As noted above, our members translated the pledge into their respective languages, whilst adding in their own logo into the pledge. In one case, the Finnish association, Muistiliitto, adapted the pledge document, translating it into Finnish, whilst also adapting it into its own branding.

Additionally, our members used different resources and approaches to raise awareness of the campaign and to encourage candidates to sign up. The Alzheimer Society of Ireland utilised the pledge image which incorporated their own logo, directly messaging candidates on Twitter. Elsewhere, Spominčica in Slovenia publicised the candidates who had signed the pledge with the photo of the candidate and, where provided, a copy of the completed pledge on their website.

Finally, our colleagues at France Alzheimer created a detailed campaign page within their website outlining the importance of dementia as a European policy priority, including an interactive map displaying information about dementia policy within different European countries country, including the number of people with dementia, whether it had a dementia strategy etc.

**Next steps for Alzheimer Europe**

We would like to thank all our members who supported this campaign and who took the time to engage with the candidates in their own country. Without their effort and support, we could not run these kinds of campaigns.

Alzheimer Europe welcome ideas and suggestions from members and others about how, when running similar campaigns to the #DementiaPledge2019 in future, we could improve upon this work. Please send any comments to: info@alzheimer-europe.org

Finally, on pages 21 we outline what steps we will be taking as part of our policy activities at a European level, including those relating to the EU institutions and the timelines for such activities.
European Working Group of People with Dementia supports Alzheimer Europe’s Dementia Pledge campaign

In late 2018, a new two-year term began for the European Working Group of People with Dementia. This article introduces the group’s members. For the purposes of Alzheimer Europe’s #DementiaPledge2019 campaign, group members shared their thoughts on why MEPs should ensure dementia is a policy priority, both at national and European level.

The European Working Group of People with Dementia (EWGPWD) was launched by Alzheimer Europe and its member associations in 2012. The group is composed entirely of people with dementia, nominated by their national Alzheimer associations. They work to ensure that the activities of Alzheimer Europe duly reflect the priorities and views of people with dementia. The EWGPWD for the term 2018–2020 has 13 members from across Europe.

The members

**Idalina Aguiar** (Portugal), joined the group in 2016. She was born in 1940 in Madeira. Idalina was diagnosed with Alzheimer’s disease in 2012 and since then, she and her family participate in different activities of the Madeiran delegation of Alzheimer Portugal. She and her daughter, Nélida, are of the opinion that a balance between drugs and complementary therapies is ideal. They try to combat the stigma around dementia and Idalina feels that being a member of the EWGPWD is an opportunity to show others that people with dementia can be active members of society. Since joining, she has been contributing to many changes in the fight against stigma and advocacy for people with dementia and their carers.

**Stefan Eriksson** (Sweden), joined in 2018. He is from a small island called Kalvsund, just outside Gothenburg. Stefan spent many years working on power plants around the world. He mostly worked in the US, Sweden and Africa. In September 2017, Stefan was diagnosed with Alzheimer’s disease. He has always been active in sports and still likes to go to the gym. After the diagnosis, he started doing gardening and enjoys time outdoors.

**Tomaž Gržinič** (Slovenia), joined in 2017. He was born in Ljubljana in 1952 and spent most of his career at a famous Slovenian graphic design company. Right now, he still occasionally works on editing and designing articles. He was diagnosed with Alzheimer’s dementia in 2016 and joined the Slovenian working group for people with dementia in 2017, where he was elected President. Support from his closest family and friends plays a major role in his everyday life. Tomaž is retired, but is still very active. He has a special interest in sailing and in summer, he goes on sailing holidays with a close group of friends. He is happy to be in the EWGPWD and to share his experiences of how to live well with dementia.

**Amela Hajric** (Bosnia and Herzegovina), joined in 2016. She shares information about the work of the EWGPWD at meetings organised by her national member association, Udruženje AiR and at the Center for dementia in Bosnia and Herzegovina. Amela says she finds the EWGPWD meetings and other Alzheimer Europe events very enjoyable and useful and she was proud to be one of four EWGPWD speakers at the group’s special symposium, “We continue to be ourselves” at the 27th Alzheimer Europe Conference in Berlin, in October 2017.

**Carol Hargreaves** (UK – Scotland), joined in 2016. She had already joined the Scottish Dementia Working Group in 2013 and became its Vice-chairperson in 2017. Since joining these groups, Carol feels like she is doing something positive with her life and loves working with other people, having fun and learning new things. She aims

I think it is important to support people with dementia and their families. That is what I want candidates to focus on if elected. They should recognise the dedication and hard work of informal carers and uphold their rights.”

**Idalina Aguiar**

“Like all of the people with Alzheimer’s disease in Sweden, I need the support of the Swedish MEPs. They must ensure we have adequate services, in particular for younger people with Alzheimer’s disease like me.”

**Stefan Eriksson**
to use her knowledge and experiences to influence at a European level.

**Bernd Heise** (Germany), joined in 2018. He is married and lives in Munich with his wife. For 34 years, he had worked as a developer engineer of semiconductor devices in the telecommunications industry, until he was diagnosed with Alzheimer’s disease in early 2016. He is also a member of the Advisory Board of People Living with Dementia, founded by the German Alzheimer association (Deutsche Alzheimer Gesellschaft e.V. Selbshilfe Demenz).

**Miha Kastelic** (Czech Republic), joined in 2018. Miha is originally from Ljubljana, Slovenia, but has been living in the Czech Republic since 2008. He spent many years working in the cleaning business, in different regional sales and marketing positions. He travelled all over Europe for many years and spent a lot of time with sales teams working on many hygiene projects for key clients. In December 2017, Miha was diagnosed with early onset Alzheimer’s disease.

**Petri Lampinen** (Finland), joined in 2017. He was diagnosed with Fronto-temporal Dementia (FTD) in 2015. He has not allowed the difficulties associated with his dementia to defeat him, and in spite of them, continues to live an active life. He enjoys working in his garden, cycling and also plays ping-pong and badminton. He finds that being open about his condition and trying to remain as calm as possible in any situation helps him to navigate life with dementia, with the support of others when needed. Petri is happy to share his ideas and thoughts with others.

**Thomas Maurer** (Switzerland), joined in 2018. He is also a member of the Swiss working group of people with dementia, formed by Association Alzheimer Suisse. Since being diagnosed with dementia, Thomas is increasingly convinced that he must and wants to play an active role in groups like this, and believes the perspectives of people with dementia are essential to the work of Alzheimer associations. He hopes to inspire others and refuses to be defined by his illness. Thomas keeps fit with a lot of sport, especially running, and he recently completed the Tokyo marathon in Japan (3 March 2019).

Dementia knows no borders or states. It affects the lives of many people and it is our common challenge. Everyone, including Finnish MEPs, must drive progress in this area.”

**Petri Lampinen**

I need the support of all UK MEPs to lead the way in further development of all the services and research that all people affected by dementia need.”

**Chris Roberts**

**Helen Rochford-Brennan** (Ireland), joined the group in 2014 and has been its Chairperson since 2016. She was previously a Chair of the Irish Dementia Working Group and remains a member today. Helen uses her time with both groups to raise awareness of dementia and raise the profile of human rights for people with dementia. She spent many years working in the tourism and disability sectors and has also devoted tireless years to community activism, working at board level in several organisations. In July 2012, Helen was diagnosed with early onset Alzheimer’s disease.

I feel privileged that Irish MEPs are leading the way in making dementia a European issue, to know I have the support of my public representatives gives me hope. Living with a progressive incurable condition, hope is fundamental to my wellbeing.”

**Helen Rochford-Brennan**

**Geert Van Laer** (Belgium), joined in 2018. He was born in a small village called Merksplas in Belgium. His father was a dairy farmer but he chose to study digital technology. He worked for 30 years as a telecom software engineer and he spent a long time in Norway, Germany, Israel and China for his job. Even when in the head office in Antwerp, Belgium, he worked with people from all over the world. In 2017, he got a diagnosis of early stage dementia. He is also a member of the recently-formed Flemish dementia working group in Belgium.
At Amgen, we believe that the answers to medicine’s most pressing questions are written in the language of our DNA. As pioneers in biotechnology, we use our deep understanding of that language to create vital medicines that address the unmet needs of patients fighting serious illness – to dramatically improve their lives.

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Amgen is proud to support Alzheimer Europe

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See the difference with TENA

TENA Pants have proven benefits that can make a real difference to the quality of life for individuals living with dementia and those that care for them. This is recognised in a study* in the UK where it says that the two most important benefits TENA Pants provides are skin integrity and comfort.

*C Knifton, Selecting absorbent incontinence pads for people with Dementia, Nursing Times, May 2018;114 (5).
European Parliament elections and campaign results – what now?

With the European Parliament elections now concluded and the political composition of the parliament now clear, we take a look at the outcome of the elections, who signed up to our campaign and what this means for Alzheimer Europe’s policy work.

The European Parliament elections took place between 23–26 May 2019, allowing citizens from 28 countries to vote for the 751 MEPs who would represent them in the European Union’s directly-elected body.

It had been anticipated that 27 countries would vote for 705 MEPs (with some reallocation of the UK’s 73 seats), however, following the extension of the UK’s date of departure from EU, the elections proceeded unchanged from 2014.

Number of MEPs broken down by party

The majority of national political parties are affiliated to a European Party or Grouping within the European Parliament. As the European People’s Party (EPP) won the most seats in the parliament, their “Spitzenkandidat” (lead candidate), it is likely that Manfred Weber MEP, will be put forward as the candidate for the Presidency of the European Commission, subject to a vote of Parliament. The provisional result of the election can be seen in Table 1.

Number of candidates signed up to the pledge

In the months running up to the European Parliament elections, Alzheimer Europe, working with our national member organisation, asked all candidates standing in the election to sign up to the #DementiaPledge2019 (more information on the campaign itself can be found on page 16). With the support of our members, a total of 230 candidates from 23 countries signed up to the pledge!

Broken down by European Parliament Group, the number of pledges can be seen in Table 2.

Broken down by country, the number of candidates signed up to the pledge can be seen in Table 3.

Table 1

<table>
<thead>
<tr>
<th>Party Grouping in the European Parliament</th>
<th>Number of MEPs</th>
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<tbody>
<tr>
<td>European People’s Party (EPP)</td>
<td>179</td>
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<tr>
<td>Progressive Alliance of Socialists and Democrats (S&amp;D)</td>
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<tr>
<td>Alliance of Liberals and Democrats for Europe (ALDE)</td>
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<tr>
<td>Greens/European Free Alliance (Green/EFA)</td>
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<tr>
<td>European Conservatives and Reformists (ECR)</td>
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<td>Europe of Nations and Freedom (ENF)</td>
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<tr>
<td>Europe of Freedom and Direct Democracy (EFDD)</td>
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<td>Non-Inscrits/Independents (NI)</td>
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<td>Other</td>
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Table 2

<table>
<thead>
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<th>Party Grouping in the European Parliament</th>
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<tbody>
<tr>
<td>European People’s Party (EPP)</td>
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<tr>
<td>Progressive Alliance of Socialists and Democrats (S&amp;D)</td>
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<tr>
<td>Greens/European Free Alliance (Green/EFA)</td>
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</tr>
<tr>
<td>European United Left - Nordic Green Left (GUE/NGL)</td>
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</tr>
<tr>
<td>Alliance of Liberals and Democrats for Europe (ALDE)</td>
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<td>European Conservatives and Reformists (ECR)</td>
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<td>Europe of Freedom and Direct Democracy (EFDD)</td>
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<tr>
<td>Europe of Nations and Freedom (ENF)</td>
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<tr>
<td>Non Inscrit/Not Affiliated/ Other</td>
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</table>

Table 3

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<th>Country</th>
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<td>Austria</td>
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<tr>
<td>Bulgaria</td>
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<td>Croatia</td>
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<td>Cyprus</td>
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<td>Romania</td>
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<td>Sweden</td>
<td>1</td>
</tr>
<tr>
<td>United Kingdom</td>
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</table>
Next steps in our policy work

Although the new Parliamentarians will not take up their seats until the 2 July and the new Commission will likely not formally assume their roles before 1 November, there is much work for us to do, to establish the foundations of our engagement with these key decision makers.

In the first instance, our priority will be to formally re-establishing the European Alzheimer’s Alliance (EAA), following up with elected members who signed the pledge, asking them to confirm their commitment to the EAA. We will also seek to identify which MEPs will sit on committees such as the Employment and Social Affairs committee (EMPL), the Environment, Public Health and Food Safety committee and (ENVI) and the Industry, Research and Energy (ITRE) committee.

Alzheimer Europe will also work with partner organisations including the European Disability Forum, European Patients Forum and members of the EU4 Health campaign to identify mutual areas of interest and to share knowledge on MEPs likely to be supportive of issues related to health and research.

A similar process will be undertaken to identify the policy priorities of the new Commission, establish connections with the Commissioners for Health, Research and Social Affairs, as well as seeking opportunities to contribute to the legislative proposals that will be brought forward. In addition, we will work to ensure that key areas such as the Work Life Balance, Accessibility Act and European Pillar of Social Rights, are maintained as priorities among the new areas of focus for the new Parliament and new Commission.

Additionally, we will work directly with our members to them to help foster stronger connections between MEPs and national members, as well as between MEPs and EWGPWD. This will include encouraging AE members to proactively engage with MEPs from their countries when attending Public Affairs meetings in Brussels (e.g. inviting MEPs to attend Lunch Debates, asking for meetings to discuss dementia, European priorities, etc.).

As the 2014-19 session of the European Parliament drew to a close, the EAA had 161 Members from all 28 Member States.

European Alzheimer’s Alliance welcomes new Chairperson

We are delighted to announce that Sirpa Pietikäinen MEP (Finland) has agreed to be the Chairperson of the European Alzheimer’s Alliance (EAA) going forward, following the retirement of Francoise Grossetete, who stood down at this election. We would like to thank her for her time as Chairperson.

The European Alzheimer’s Alliance (EAA) has been active in the European Parliament since 2007. The EAA is a non-exclusive, multinational and cross-party group that brings together Members of the European Parliament (MEPs) to support Alzheimer Europe and its members in making dementia a public health priority in Europe.

The mission of the EAA is to:

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

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As the 2014-19 session of the European Parliament drew to a close, the EAA had 161 Members from all 28 Member States.
European Disability Forum campaigns on voting rights for persons with disabilities

Policy Coordinator Alejandro Moledo explains how the European Disability Forum (EDF) has been campaigning to change legal and physical barriers, which prevent as many as 800,000 persons with disabilities from voting.

Adolfo’s story

In 2007, Adolfo Barroso was 20 years old when he tried to vote for the first time. It was not just any election, it was a referendum about his region (Andalusia, in Spain). However, when he arrived at the polling station he found that he was not on the electoral register. With no explanation given for his omission from the register, he felt annoyed and invisible, and since then, he started to fight to regain his right to vote. The court and authorities finally explained to him that he was deprived of his voting rights because of intellectual disability. They did not want others to take advantage of him, they said – as though other voters are immune to influence by media or politicians. Adolfo did not give up. He went through a lengthy, complicated process, to different courts and doctors. He had to answer irrelevant questions such as “what is the speed of light?” or “who was Catherine the Great?” – as though all voters would know these things, or that these were necessary to decide who to vote for. Last year, Adolfo regained his right to vote, shortly before Spain finally recognised the political rights of over 100,000 persons with intellectual disabilities, giving them the opportunity to vote for the first time in Spain’s recent elections.

The current situation in Europe

At the time of writing, there were still 800,000 people with intellectual or psychosocial disabilities in the EU who were unable to vote in the European Parliament elections. Persons with disabilities have different democratic rights depending on the country they live in. There has been progress in some countries recently: Spain, France, Denmark, and Germany. Nevertheless, there are 16 Member States in which persons with disabilities are still deprived of the right to vote. They are treated as second-class citizens who need others to decide for them. This is unacceptable, anti-democratic and goes against core EU values and the UN Convention on the Rights of Persons with Disabilities (UNCRPD).

It is not only lack of legal capacity that prevents persons with disabilities from voting. Millions of persons with disabilities cannot vote simply because of accessibility barriers:

- from the political information (e.g. inaccessible websites and electoral programmes, candidates’ debates without captions, events without sign language interpretation), to voting itself (e.g. inaccessible voting station, lack of assistance, impossibility for blind people to autonomously pick the ballot).

This is why the European Disability Forum (EDF) is fighting for full political participation and elections for all.

EU-level action in recent years

Why go to all this effort? Since a reference to persons with disabilities was introduced in the Amsterdam Treaty in 1997, the EU has undoubtedly impacted the everyday lives of persons with disabilities and their families; although its positive measures may often be presented by national governments as their own achievement. Despite this, some of these measures are well known: the EU Health Insurance Card, the Erasmus program or the EU Parking Card for persons with disabilities. Others are less well known but equally important: EU funds supporting accessible environments and the independent living of persons with disabilities within the community; the rights of persons with disabilities to get assistance in train stations and airports; and the right not to be discriminated against at the workplace.

To shine light on this impact, EDF has produced a booklet called “Your Rights in the EU” which gathers together all the rights achieved for persons with disabilities at EU

Adolfo was denieed the right to vote

There are 16 Member States in which persons with disabilities are still deprived of the right to vote. They are treated as second-class citizens who need others to decide for them.”
level, indicating where persons with disabilities can go to make a complaint or to seek redress.

EDF’s “European elections for all” campaign

In December 2017, over 800 delegates with disabilities from all over Europe filled the hemicycle of the European Parliament and adopted our manifesto, outlining the political priorities for the next five years. We then transformed it into a political pledge for candidates standing to become Members of the European Parliament (MEPs) in the recent election. We want them to fight for:

- Fully accessible and inclusive European elections so that persons with disabilities enjoy their right to vote and to stand for election.
- A comprehensive and well-resourced European Disability Strategy 2020–2030 designed to enact and monitor the implementation of the Convention on the Rights of Persons with Disabilities.
- EU funding to secure equal opportunities and non-discrimination.
- An EU Pillar of Social Rights which improves the living conditions of persons with disabilities and their families within the society.
- A Europe of human rights by adopting comprehensive anti-discrimination legislation at the EU level.

The candidates who sign this pledge also commit themselves to re-establish the Disability Intergroup in the European Parliament, which consists of MEPs from all countries and political groups, working together for the rights of persons with disabilities.

Our campaign includes an online petition, “European elections for all”, to raise awareness of the importance of abolishing discriminatory electoral laws and of the need to ensure accessibility of the whole elections process. In collaboration with our members, we have also developed a set of accessibility guidelines for election communications that we have presented to the main European political parties and institutions, and have put together a collection of interviews to illustrate how certain barriers can affect people entitled “the Voters of Europe series”.

At the end of the day, these elections once again take us back to basics, and back to the motto that has guided the disability movement since the beginning: “nothing about us without us” – therefore, nothing about us without our votes!

These elections once again take us back to basics, and back to the motto that has guided the disability movement since the beginning: “nothing about us without us” – therefore, nothing about us without our votes!”

Supporters hold up scarves calling for the right to vote for all

The European Disability Forum is an umbrella organisation of persons with disabilities that defends the interests of over 80 million Europeans with disabilities. We are a unique platform which brings together representative organisation of persons with disabilities from across Europe. We are run by persons with disabilities and their families. We are a strong, united voice of persons with disabilities in Europe.

www.edf-feph.org
Implementing the WHO Global Action Plan on dementia


Two years on from the publication of the WHO’s Global Action Plan, Dementia in Europe caught up with colleagues from the WHO, about how the implementation of the plan was progressing. We spoke to:

- Dan Chisholm (DC), Programme Manager, Mental Health in the WHO Regional Office for Europe.
- Katrin Seeher (KS), Technical Officer, Department of Mental Health and Substance Abuse at WHO Headquarters Office.
- Michal Herz (MH), Consultant, Department of Mental Health and Substance Abuse at WHO Headquarters Office.
- Stéfanie Freel (SF), Consultant, Department of Mental Health and Substance Abuse at WHO Headquarters Office.

The WHO developed a Global Action Plan on the Public Health Response to Dementia 2017–2025. Could you share with us some of the work and progress that has taken place since?

DC: The action plan was endorsed two years ago by all 194 WHO Member States and urges them “to develop, as soon as practicable, ambitious national responses to the overall implementation”.

The plan contains seven distinct action areas, spanning policy development, risk reduction, enhanced diagnosis and care, improved support for carers as well as better information and surveillance. What I really like about this plan is the development and availability of specific, practicable tools or guidance for each action area to support implementation efforts at the country level, and for this we should acknowledge the strong contribution of external experts and partners like AE and Alzheimer’s Disease International (ADI) as well as the dementia team at WHO Headquarters who coordinated these developments.

Without these robust tools, there is a heightened risk of delayed or inconsequential action at the national or regional level.

To give you two examples of recently developed tools. The first is in support of dementia as a public health priority; it is a WHO Guide that provides a step-by-step process through which national authorities and stakeholders can identify needs, priorities and a local framework for action. It is being used as a framework for revising the national action plan in the Czech Republic, for instance.

The second example is new WHO guidelines on risk reduction, which show that acting on the behaviours that increase the risk of dementia – such as tobacco cessation, physical activity and healthy diet – are the very same as those for other diseases like cancer, diabetes and stroke. The guidelines can be used for enhanced advocacy and training as well as linking to the broader noncommunicable disease agenda.

How is implementation proceeding, and what have been the challenges?

KS: As expected in a region with more than 50 Member States, the rate and speed of implementation is variable! For some action areas, such as collection a core set of dementia indicators, we have seen widespread interest and uptake. Since 2017, when we had 8 countries that are Alzheimer Europe members contributing to the pilot phase of the Global Dementia Observatory (GDO) was in its pilot phase, we now have 24 more countries who have either submitted data, are collecting data or in the process of exploring participation. A particular challenge for this action area of course concerns the complex collaborations needed to collect this data across different sectors or parts of government.

DC: But for other action areas the situation is very different. For example, only sixteen out of 53 Member States in the WHO European Region have so far developed a national action plan for dementia, which indicates an insufficient level of preparedness to respond effectively to this public health challenge. Related to this point is the awareness about the action plan itself and the tools on offer;
I was quite taken aback when, at AE’s conference last year in Barcelona, no more than one in ten delegates signalled that they had heard of this plan or some of its components. If that is taken as a marker of the level of awareness in the dementia field, you can only imagine what it might be at the national level in some parts of the Region. We clearly have a big task in communicating more effectively and widely the key elements of WHO’s – and indeed other partners’ – work in the area of dementia policy, planning and practice.

You mentioned some implementation tools already; are there others we should know about?

**SF:** Dan had already referred to the new policy guide and risk reduction guidelines as well as the GDO, but yes, there are others too. The second action area – dementia awareness and friendliness – is another one we have been working on intensively. We are in the final stages of developing a DFI (dementia friendly initiatives) toolkit which will be launched later in the summer. Dementia-friendly initiatives are activities that enable people living with dementia to live their life to its full potential with dignity, respect, independence, choice and control, without stigma and discrimination, where they are fully included in society. To create the tool kit, we aimed to get as comprehensive a perspective on this as possible. Therefore, 20 in-depth interviews took place, over 150 participants completed a detailed survey, and 5 focus groups presented the opportunity to get an in-depth understanding of this topic. In all, participants from 46 countries were consulted as part of the development of the toolkit.

**MH:** In addition, the iSupport online skills and knowledge training programme for carers of people with dementia is being adapted in 8 countries. Following requests from several countries and to ensure a broader reach of the programme, iSupport is being adapted into a printable manual. This will be available to download from WHO’s website imminently. Similarly, the iSupport online carers training is now also being adapted in several countries and the e-learning tool is being converted to a hard-copy manual.

**What are the next steps for WHO?**

**DC:** WHO will continue to work at global, regional and national levels to support and strengthen countries’ efforts with respect to key functions like providing the normative basis for action (e.g. development of standards, tools and guidelines), developing information and monitoring systems (through the GDO), and enhancing leadership/advocacy. One upcoming event at the Regional level that we are looking forward to is a dementia policy and planning workshop that is being kindly hosted by the government of Malta; it aims to provide selected countries of the Mediterranean basin who are in the early stages of national planning with the opportunity to share experiences, exchange knowledge and refine implementation strategies. It will be similar in intent to an earlier workshop that took place last year in Sarajevo, at which civil society and government representatives as well as health care providers from countries within and beyond the Western Balkans met to share their knowledge, needs and expectations.

**KS:** More broadly, and at a global level, we plan to expand the GDO knowledge exchange platform, which contains key resources to support the implementation of the global dementia action plan and enhance countries’ response to dementia. The knowledge exchange platform will provide a space for all relevant stakeholders to share resources (e.g. good policy, guidelines and practice examples for dementia), which can facilitate mutual learning and promote the exchange of good practices in the area of dementia. A comprehensive peer-review process consisting of experts (both by experience and by profession) will ensure that submitted resources meet developed quality and good practice criteria. We are hoping to start requesting resources to be submitted to the knowledge exchange platform in the Autumn.

For more information: www.who.int/mental_health/neurology/dementia/en/
Spanish Minister outlines the content of the country’s National Alzheimer’s Plan 2019–2023

Speaking at a press conference, the Minister of Health, María Luisa Carcedo, outlined the content of the country’s forthcoming dementia strategy.

On 27 April, the Spanish Government’s Minister of Health, Consumption and Social Welfare, María Luisa Carcedo, announced that the country’s National Alzheimer Plan had been presented to the Council of Ministers, and outlined its contents. The Plan aims to reduce the impact of the disease by promoting the ability of the person with dementia to continue to live within their environment, implementing the necessary social and health responses and improving knowledge regarding the needs of people with dementia and their families.

As part of this, early detection is a key area of focus, including improvements in the diagnostic capabilities of the system, as well as promoting research on the origin, diagnosis and treatment of the disease. In addition, there are proposals to develop information and awareness programmes for health professionals, specifically around signs and symptoms of the disease.

In relation to the economic and social impact of the condition, the Plan will include measures to support family caregivers through protection systems, such as social security, employment or housing. Included within this are measures such as the training of primary care professionals to detect overload and stress situations of family caregivers.

The plan further considers the need to involve all stakeholders and society in responding to the condition, aiming to remove stigma and exclusion of persons with dementia in society.

The plan establishes four lines of action:

- Research on the determinants of the disease.
- The development of health promotion policies, as well as progress in the early diagnosis and the selection of the most appropriate treatments.
- Improvement in services, supports and benefits.
- Raising awareness and improving societal attitudes in relation to dementia.


Alzheimer Europe’s two Spanish member organisations have welcomed the content and approach of the National Alzheimer’s Plan 2019–2023.

Response from Confederación Española de Alzheimer (CEAFA) President, Rosa María Cantabrana Alutiz

What does the Minister’s report to the Council of Ministers mean? It means that there is a real political will to work right now to address the consequences of Alzheimer’s disease in Spain. The National Alzheimer’s Plan has already been launched.

Since 2010, Confederación Española de Alzheimer (CEAFA) has been demanding an Alzheimer’s disease state policy. That year, the Alliance for Alzheimer’s was born under the auspices of CEAFA. The Alliance was the precursor to what would later become the State Dementia Group. At that time, the Alliance claimed that the creation of a National Alzheimer’s Strategy would respond to the needs of the patient-caregiver binomial and promote socio-health care, research, training and legal protection for those affected by the consequences of dementias. The four objectives of the first National Alzheimer’s Plan include those issues.

In 2013, upon the request of the General Directorate of Instituto de Mayores y Servicios Sociales (IMSERSO), the State Dementia Group was constituted on the old Alliance for Alzheimer’s. Since then, CEAFA is part of the Permanent Commission of the group.

The State Dementia Group has, for CEAFA, been one of its greatest achievements in its desire to represent and defend the rights of people affected by the consequences of dementia. CEAFA has invested in the State Dementia Group all its effort and all the knowledge that its wide and dense associative network has been accumulating for more than 40 years.

The Confederation has always maintained that to obtain results in the fight against dementia, it is necessary to join forces, sharing information and knowledge, and supporting each other. And now we have results. Spain already has the first National Alzheimer’s Plan, a great achievement for CEAFA but also, a great challenge. CEAFA is committed from now on to work hard to fulfil the objectives that the Plan proposes. CEAFA commits itself to work so that the first National Alzheimer’s Plan leads to a state policy for Alzheimer’s disease.
Response from Fundación Alzheimer España Chairperson, Micheline Selmes-Antoine

The Spanish Health Minister announced the Government’s interest to be in-line with other European plans for dementia (including Alzheimer’s disease) following the European Directrices and World Health Organization (WHO) recommendations.

As may will be aware, following the election in Spain, the government continues as before until agreements between PSOE (the party with the greatest share of the votes) and others partners can be reached, as they don’t have the necessary parliamentary representation to govern alone.

The most interesting points of the plan are:

- They enlarged the target of specialists, especially taking into account GPs, for the first steps to access to a possible dementia diagnosis in line with the Spanish structure (Seguridad Social).
- They are insisting on early diagnosis as fundamental part of the possible solutions for people with dementia and their families.
- They are proposing to create a large national campaign to inform each citizen about Alzheimer's disease (using TV, radio, movies, etc.).

However, the most important aspect is the Inter-territorial Committee which is the main powerful tool to improve this plan in each of the 17 Autonomous Communities which make up Spain. This committee asked ensured the possibility of each Autonomous Community to work on the plan according their regional policies.

For us, it means that, hopefully, the Regional Health and Regional Social Welfare will take time and measures to provide our Alzheimer’s community with adequate regulation, as well as ensuring that people have the possibility to have an early diagnosis. For informal caregivers (and formal caregivers as well), they should be able to get access to the best services for each step of this illness, which continues to be underdiagnosed and without pharmacological treatments.

In our local experience, specialists such as Neurologist, Geriatricians, Psychiatrists, Psychologists and GPs are concerned and are making excellent progress in pushing to have a draft solution as soon as possible.

Finally, the next European elections will be important, especially as Spain can’t afford to have more time outside the development of European dementia policy.
European research landscape set for significant changes following agreements and reorganisation

Recent agreement on the future of Horizon Europe between the European Parliament and Council, as well as significant restructuring of the Commission’s Directorate General for Research and Innovation, mean that the future of European research will be radically different.

Horizon Europe agreement

The EU has reached agreement over the future of the Horizon Europe (2021–2027) research programme, the successor to the current Horizon 2020 programme.

The agreement, reached between the European Commission, Council and Parliament, sets out the legal basis for the future programme, as well as establishing its priorities. However, many aspects in relation to the operational details of the programme and the budget have yet to be agreed. Despite this, the European Commission is now able to begin the more detailed work around strategic planning and preparatory work for the future programme.

Outline of the programme

Horizon Europe is underpinned by three “pillars” which set the overarching aims of the programme. The first pillar is designed to support basic science, strengthening the EU’s scientific leadership and develop high-quality knowledge and skills. The second pillar will support research to address societal challenges and industrial technologies in areas such as health, security and digital, as well as those technologies related to climate, energy, mobility, food and natural resources. The third pillar will focus on scaling up innovations through a newly established European Innovation Council.

Under pillar two sits a new feature of Horizon Europe: “research missions”. These special areas of focus will receive dedicated funding, and are intended to make it easier for citizens to understand the value of investments in research and innovation, as well as maximising the impact of investments. Mission areas have been created, under which, more focused missions will sit. The five mission areas are:

1. Adapting to climate change, including societal transformation
2. Cancer
3. Healthy oceans, seas, coastal and inland waters
4. Climate-neutral and smart cities
5. Soil health and food

Industry partnerships, such as the Innovative Medicines Initiatives (IMI 1 & 2) will also continue to be a considerable part of the Horizon Europe programme. However, the agreement attempts to streamline the existing number of partnerships however it is expected that some partnership areas may have more than one partnership. The eight partnership areas are:

1. Faster development and safer use of health innovations for European patients, and global health.
2. Advancing key digital and enabling technologies and their use, including but not limited to novel technologies such as artificial intelligence, photonics and quantum technologies.
3. European leadership in metrology, including an integrated metrology system.
4. Accelerate competitiveness, safety and environmental performance of EU air traffic, aviation and rail.
5. Sustainable, inclusive and circular bio-based solutions.
6. Hydrogen and sustainable energy storage technologies with lower environmental footprint and less energy-intensive production.
7. Clean, connected, cooperative, autonomous and automated solutions for future mobility demands of people and goods.
8. Innovative and R&D intensive small and medium-sized enterprises.

Change in responsibilities

The new agreement has shifted the responsibility of different institutions of the EU, changing the way in which the three institutions influence the programme.

During the negotiations, there had been debate about the role of Parliament in relation to the “Specific Programme (which sets out the details of Horizon Europe’s various elements) and the Framework Programme (which sets out the overall structure and decides the budget).

Under the agreement, the Parliament will retain its role in approving the Framework Programme, whilst relinquishing its vote in
relation to the Specific Programme. Additionally, Parliament will also allow the Council full power to approve the strategic planning, which will be drafted in the first instance by the Commission. In doing so, it has secured greater control over the themes for the research partnerships and the missions, which will be contained within the Framework Programme.

**Budget for Horizon Europe**

The Commission has proposed a budget of EUR 94.1 billion for Horizon Europe, whilst the parliament has supported a budget of EUR 120 billion. The overall budget for the programme will be decided as part of the Multi-annual Financial Framework (MFF), the process for agreeing the seven year budget cycle of the EU.

Due to difficulty in reaching agreement over the future budget, in December 2018 Commissioner for Budget and Human Resources, Günther Oettinger, pushed the deadline for agreement to October 2019, having previously expected this to conclude in May 2019.

This is significant as decisions related to the Horizon Europe around the involvement around third countries (i.e. non-EU countries) will be agreed as part of this process.

As such, the newly elected parliament will play a significant role in key decisions around the future of the research programme.

In the current research programme, researchers in non-EU countries that have association agreements with the EU – such as Norway, Switzerland, Israel, and Turkey – can apply for Horizon 2020 grants. Those in countries without association agreements can participate in Horizon-funded research projects if they cover their own costs (with some allowances for lower-income countries).

However, it is not clear that such arrangements will continue in their current form and with the extension of the budget process, clarity may not arrive for some time.

**Future of UK involvement in EU research**

Compounding the uncertainty over this area is the protracted Brexit process. The UK was due to leave the EU on 29 March 2019, but this has been extended until 31 October 2019 (at the latest). However, as it is still not clear (at the time of writing) whether the UK will sign the Withdrawal Agreement or whether the Political Declaration will apply, thus creating uncertainty around the nature of the future relationship between the two countries.

At present, the UK is a major contributor, participant and beneficiary of the Horizon 2020 research programme, being the second largest recipient of funding overall, with approximately 15% of grants distributed through the programme since 2014 (equivalent to around EUR 5.7 billion). In relation to dementia research, UK researchers have been involved in some of the most prominent research projects including EPAD, ROADMAP and PARADIGM.

Whilst Carlos Moedas, the Commissioner for Research, Science and Innovation has publicly been supportive of the UK’s continued involvement in the programme, the deadline for the UK’s exit coincides with the end of the mandate of the current Commission. As such, with a new European Commission and Parliament likely to be in place for the next stage of discussions, the future of UK involvement remains uncertain.

**Research directorate restructured**

EU Commissioners have approved the details of a new “matrix” design for the Directorate General of Research and Innovation (DG RTD), which aims to break down “silos” of working and establish relationships across other areas of the Commission.

The re-organisation is seen as a preparatory step in advance of Horizon Europe and has been overseen by Director General Jean-Eric Paquet. The changes will take effect from 1 June 2019.

To handle specific policy areas, the RTD will have four thematic areas: “healthy planet”, “clean planet”, “people” and “prosperity”, with nine directorates. Of particular interest for dementia research in Europe will be the directorates of “people” which will deal with health matters, and that of “policy and programming” which will oversee Horizon Europe.
Dementia carers should have better support and more recognition

Four carers’ organisations in Europe discuss their advocacy work and detail the support currently available to carers in their countries. There are differences between them, but the overall message is the same: carers are in urgent need of more support and policymakers must do better by them.

National Dementia Carers Action Network – An evolving model of campaigning and representation work in Scotland

Alzheimer Scotland’s National Dementia Carers Action Network (NDCAN) is a campaigning group in Scotland funded by the Scottish Government, supported by Alzheimer Scotland. Members are carers or ex-carers of people with dementia, who advocate for the rights of carers and for better dementia-specific support services.

The group provides a strong collective voice for unpaid carers to influence Scottish dementia policy and practice, and inform Alzheimer Scotland’s policy priorities. With members on the Board of Trustees of Alzheimer Scotland, unpaid carers contribute to the governance arrangements of the organisation.

Alzheimer Scotland established NDCAN in 2011, in recognition of the impact of dementia on unpaid carers across Scotland who felt unrepresented. Eight years later, NDCAN has built a formidable reputation as a national campaigning group.

How NDCAN works

Being supported by a small staff team and wider resources of Alzheimer Scotland provides significant advantages, including access to current policy and research evidence and links to Alzheimer Scotland’s local involvement networks.

NDCAN contributed to consultation on the Carers (Scotland) Act 2016, implemented in 2018, and the Carers Charter in Scotland. The Act grants new rights to carers, such as the right to an adult carer support plan or young carer statement and the right to be involved in decisions about the support they or the person they care for receives. It also sets out a series of duties for local authorities in areas such as eligibility criteria, information and advice, and the development of a local carer strategy.

Scotland has some positive provisions, which carers may be eligible for, including a carer allowance, among other benefits, but there are complex, varied eligibility criteria applied at local level. The overall support envisioned by the Carers Act must be considered against the backdrop of the significant emotional, financial and health impacts of caring.

Health and Social Care system reforms are shifting more caring services to the home and community. The essential contribution of unpaid dementia carers in Scotland should be protected and invested in and the human rights and unique personal needs of dementia carers must be at the forefront of effective policies. Quality carer support services and involvement of carers in service planning is variable across Scotland because control of implementation of strategy commitments happens at local level.
An increasing focus on influencing locally

NDCAN members raise issues from carers across Scotland in their campaigning and awareness activities. There are around 60 members across Scotland, based in 21 out of the 32 local authority areas. In 2017–2018, around 50 local events were run by service teams, reaching over 1,000 service-users, to hear their views and issues.

Influencing how well national strategies are delivered locally is pivotal to the overall improvement of services to people with dementia and unpaid carers, and this is now a major focus for NDCAN.

NDCAN committee member and carer Janette Kean says:

“Our work to improve policy and practice must be persistent at all levels, international, national and locally. We are realising how important influencing local decision makers is to making progress.”

The Dementia Carers Campaign Network (Ireland)

“It’s like we’re screaming but it’s a silent scream”. This is how a carer at The Alzheimer Society of Ireland’s (ASI) recent Emergency Dementia Summit described his role of caring for his mother who lives with Alzheimer’s.

In Ireland, there was no mention of dementia in Budget 2019 and there are thousands of carers across the country in desperate need of supports. Personal stories by carer advocates are essential to raise public awareness and, indeed, to finally prompt the Government into action. This is why the Dementia Carers Campaign Network (DCCN) exists.

Established in 2013 by The ASI, the DCCN is a national advocacy group that presents a vital opportunity for carers to use their voice to raise awareness of issues affecting families living with dementia in Ireland. It is estimated that 500,000 people in Ireland have families who have been affected by dementia and the DCCN meets the needs of these people by highlighting the issues that affect carers and advocating for better services and supports.

Carers are too busy caring to be able to march to Government buildings in great numbers; they are too tired, caring with little respite, to have the energy to lobby; and they are too burdened, caring with little support, to have the opportunity to fight for what they require. Without carer advocates, such as those in the DCCN, telling their personal stories, who would speak for carers that are in desperate need of supports and services?

What does the DCCN do?

Members of the DCCN engage in a wide range of activities seeking to effect positive change for people with dementia and carers. They use their personal stories to create awareness raising campaigns, to contribute to research and to inform policy. When members speak publicly, they are sharing their own stories and not that of the person living with dementia, because the illness affects more than the person who is diagnosed. Carers have often given up their careers, their financial stability and their personal lives to care for a loved one with dementia.

In addition to these activities, the group runs an awareness campaign each year. Previous campaigns have examined the impact of caring for a loved one with dementia, and the supports carers need at different stages of their journey. Both were social media-based campaigns. In 2018, in conjunction with the Irish Dementia Working Group (IDWG), DCCN members created a campaign on the experience of diagnosis which was aimed at the health sector. It was delivered via a video and multiple presentations by members to health professionals. The video can be viewed on The ASI YouTube channel via this link: www.youtube.com/user/AlzheimerIreland
In Portugal, there are about 800,000 informal carers, who give up their professional, personal and social lives to care for their loved ones, 24 hours a day. There is no real support for them and they are in desperate need. Nélida Aguiar – who cares for her mother, Idalina Aguiar, a member of the European Working Group of People with Dementia (EWGPWD) – belongs to a group of carers, fighting for the rights of informal carers and their recognition: The Associação Nacional de Cuidadores Informais (ANCI) – The National Association of Informal Carers. ANCI organises a variety of initiatives, awareness-raising actions, demonstrations and vigils.

How did ANCI come into being and what is it working towards?

Being an informal carer can lead to a significant physical, psychological, social and financial overload. From a group of carers and former carers of relatives with dementia, a national movement emerged that gave rise to the present association. ANCI is made up of children, wives, husbands, grandchildren, brothers, sisters, fathers, mothers, and friends of people with very diverse pathologies.

Some social supports do exist in Portugal, but they are still scarce, and since it is thought that in the next 10 years there will be a 40% increase in the number of people with dementia, scarce is not sufficient. There is a significant shortage of formal care, which places far too much responsibility on informal carers.

The provision of informal care has too heavy a cost, with huge economic, physical and psychological implications. There is a great risk of poverty, loss of employment, isolation, catastrophic impact on relationships and social life, depression, exhaustion and stress. Psycho-social support is therefore hugely important.

ANCI has a motto: “Caring for love, quality and knowledge”. To this end, they want to promote the role of the informal carer among the public and the government. They want a national Informal Carer Statute and hope to raise awareness across the whole country, as well as providing support, so that other carers do not feel alone.

ANCI wants the establishment of the national Statute to include all types of

Two distinct regional networks

The DCCN is governed by seven volunteer advocates, who form the national steering committee. There are currently 43 members on the DCCN across Ireland in two regions; the Munster Dementia Carers Campaign Network and the Leinster Dementia Carers Campaign Network. The regionalisation of the DCCN, in Munster and Leinster, gives many carers their first opportunity to actively engage in advocacy, since they are often unable to travel to participate in projects and events, due to caring and other responsibilities.

Members have opportunities to share their experiences with their local community, to lobby locally-elected representatives, and to highlight the specific needs of carers within their community through DCCN campaigns.

The DCCN needs personal stories to be heard. Members need the listener to get an insight into the challenging role of caring. They need the general public to respond, to amplify the carer voice and to make the Government hear carers’ “silent scream” for dementia supports.

The Alzheimer Society of Ireland facilitates and supports the DCCN.

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Two distinct regional networks

The DCCN is governed by seven volunteer advocates, who form the national steering committee. There are currently 43 members on the DCCN across Ireland in two regions; the Munster Dementia Carers Campaign Network and the Leinster Dementia Carers Campaign Network. The regionalisation of the DCCN, in Munster and Leinster, gives many carers their first opportunity to actively engage in advocacy, since they are often unable to travel to participate in projects and events, due to caring and other responsibilities.

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informal carers, such as the parents of children, adolescents or adults with disabilities. There will have to be specific and appropriate training for carers (qualification), and a new third-person assistance allowance should be defined for those who are beneficiaries of the full-time carer statute. Home helps and financial support are needed, as well as care plans, consultations and other public services. Psychological support should also be provided to former carers (for a minimum of 6 months).

**Political progress is happening, but it is slow**

Importantly, some political parties have begun to recognise the importance of engaging with informal carers and supporting them. In recent months, some working meetings have been established and ANCI members have been consulted on their opinions and experiences as informal carers.

**The Statute of the Informal Carer – Madeira pioneers change**

At the regional level, significant steps have been taken to recognise and support carers on the Portuguese island of Madeira. In April 2019, the Autonomous Regional Government of Madeira (RAM) unanimously approved the Statute of the Informal Carer. The Diploma presented by the Regional Government, in the Legislative Assembly of Madeira, officially recognises the role of the Informal Carer. The Region of Madeira has become a pioneer, leading the way in recognising this social function, says Nélida Aguiar. At the national level, however, discussions are still underway, but ANCI hopes that in the coming months, progress will be made for all of Portugal’s informal carers.

**Meeting the President of Portugal**

Unfortunately, the Assembly of the Republic has postponed the discussion of the proposals and no measures of protection exist, yet.

**Dementia Carers Count (UK)**

The UK is facing a crisis in care. There are currently an estimated 6.5 million family carers and 700,000 of those are unpaid family carers of people with dementia. The UK has separate health and care systems and consequently dementia is one of the most complex and challenging conditions for those sectors to support. That often means that the family carers of people with dementia receive little support at a time in their life when it can be most needed.

**Services provided to carers**

Dementia Carers Count (DCC), a new charity in the UK, is looking to fill the void. DCC has a simple, but unique vision: that all family carers of people with dementia should feel confident, supported and heard. The charity provides a range of direct services to family carers and its core service is a three-day practical course, which can help carers to build the skills and confidence to see them through the ups and downs that caring can bring, and to connect and share the load with others experiencing similar challenges. The courses are residential – carers spend two nights and three days. The education components include learning about the brain and how it is affected by different dementias. Carers also learn about themselves; how their personality type affects their caring style, how to build their resilience and retain their sense of self whilst also being an effective carer. The immersive residential component of the course means that carers form immense bonds with each other and form long-lasting peer support networks.

As well as its three-day courses, the charity also provides one-day courses focusing on specific topics such as nutrition and attachment, Carers’ Support Plans, Carers’ Coaching and Carers’ Counselling. All the services are developed and delivered by qualified and experienced health and care professionals, including occupational therapists, speech and languages therapists and clinical psychologists.

**CEO Claire Goodchild explains the DCC’s mission**

“Our mission is to provide a space where family carers of people with dementia are inspired to learn, get connected and be empowered in their caring role. The premise of our courses is that knowledge is power. Being equipped with essential information unlocks so much for family carers, we’ve already had some incredible feedback from participants, who have described the courses as truly life changing. The independent academic evaluation of the courses supports the feedback that carers give us and it’s clear the impact on individual carers is long lasting.”

“We want to work with funders and the statutory sector to develop our services as we’re responding to an urgent need – carers provide around GBP 11.6 billion worth of care every year in the UK, yet there’s very little support for them when they need help most. Carers know, in theory, that it is important to look after themselves, yet so many don’t do it.
Jayne Goodrick wins Prime Minister’s Award

Jayne Goodrick is Chair of the DCC Carer’s Advisory Panel (CAP). Jayne’s mother has a diagnosis of dementia, small vessel disease, and her husband Chris has a diagnosis of mixed dementia, vascular damage and Alzheimer’s, diagnosed at age 50. Jayne and Chris are both active members of multiple groups and committees for dementia related networks and have made several media appearances.

On 1 March (St David’s day) 2019, Jayne was awarded a “Points of Light” award by the Prime Minister which recognises outstanding volunteers who are making a difference in their community. Jayne was recognised in a letter from Theresa May for showing “remarkable resilience and dedication in so openly sharing your personal experiences of caring for your husband Chris with his diagnosis of dementia.”
Alzheimer Scotland highlights inequities in access to care

In January 2019, Alzheimer Scotland published the report “Delivering Fair Dementia Care for People with Advanced Dementia”, marking the beginning of a national campaign aiming to put an end to the inequality in access to care, faced by people with advanced dementia. Dementia in Europe caught up with James Pearson, Director of Policy & Research at Alzheimer Scotland, to find out more.

In January 2019, Alzheimer Scotland published Delivering Fair Dementia Care for People with Advanced Dementia – why did Alzheimer Scotland focus on this area?

The Delivering Fair Dementia Care in Advanced Dementia report marks the beginning of a national campaign by Alzheimer Scotland to end the inequities faced by people living with advanced dementia in the lack of access to the health and nursing care they need and the disproportionate impact of the costs of social care.

Accessing appropriate care as the illness progresses and paying for social care are among the most common issues raised by our members and the thousands of people living with dementia or caring for people with dementia who access our community support and 24-hour Freephone Dementia Helpline every week. Health care in Scotland is free and is funded through general taxation, however, social care, although mitigated to some extent by free personal care provisions in Scotland, is subject to charges. The complexity and lack of transparency of financial assessment processes for social care charging is a major concern and is often so complex most don’t understand how the process works, how the charges are calculated, or why, unlike other progressive and terminal health conditions, they are asked to pay for care. This is further compounded by the lack of access to health care in advanced dementia. In dialogue with our members Alzheimer Scotland agreed that we would explore the issues around the inequality of access to health care and paying for care in advanced illness.

As part of this Alzheimer Scotland, in November 2015, published ‘Advanced Dementia Practice Model: understanding and transforming advanced dementia and end of life care’. It sets out a comprehensive and integrated approach to providing care and support for people with advanced dementia and at the end of life. It also highlighted the inequality in access to the health care needed in advanced dementia compared to the access that exists for other progressive illnesses. A key recommendation of the report is that:

“The Scottish Government accept and recognise that on the basis of this report, there is clear evidence that once a person has reached the advanced stage of dementia, all their needs are health care needs.”

In 2017, Alzheimer Scotland established the Fair Dementia Care Commission to consider, in the context of this recommendation, how we can ensure that people in Scotland with advanced dementia have equality of access to the expert health and nursing care they need which is free in line with other progressive and terminal illnesses.
Can you tell us about the membership of the Fair Dementia Care Commission and the process of developing the report?

Alzheimer Scotland brought together a small commission, chaired by the former First Minister for Scotland, Henry McLeish, which included clinical, nursing, social work, economic and academic expertise. Crucially it also included members of Alzheimer Scotland’s National Dementia Carers Action Network who have personal experience of caring for family members with advanced dementia. The commission worked alongside Alzheimer Scotland to review how we understand and respond to the complex health care needs of people with advanced dementia in Scotland. The remit of the commission was to:

- Determine how advanced dementia is defined and recognised in practice
- Estimate the size of the population of people living with, and dying from, advanced dementia in Scotland
- Examine and describe the current charges and cost framework of advanced dementia care
- Make recommendations on what needs to change for Scotland to lead the way in achieving fair dementia care from diagnosis to the end of life.

To support these aims the commission used a combination of desk-based research methods to review the current literature on advanced dementia and existing data. The commission utilised a managed democratic approach to facilitate two meetings with expert health care practitioners and family carers to explore how to recognise and define advanced dementia in practice.

What have been the key findings of the report?

The report contains several key findings:

- Dementia is caused by progressive neurological disease processes, such as Alzheimer’s disease
- Advanced dementia produces complex health and nursing care needs
- People with advanced dementia do not currently have equality of access to the health care they need – instead advanced dementia remains essentially a social care response
- People with advanced dementia are disproportionately subject to social care charges for what are primarily health and nursing care needs
- People with advanced dementia are paying an estimated £50.9m per year in social care charges for care which doesn’t provide the health or nursing care they require
- The current system of social care charges is complex, lacks transparency and is variable across Scotland.

The report also makes several recommendations aimed at ending this inequality. They key recommendations are that:

- The Scottish Government commits to recognising that the needs of people with advanced dementia are health care needs and ensure equality of access to appropriate health and nursing care, which is free at the point of delivery
- The Scottish Government commits to investigating the costs of implementing appropriate and free health care for those living, and dying, with advanced dementia.

How has Alzheimer Scotland been campaigning to change the inequality which has been demonstrated the report?

The publication of the report marks the beginning of one of the most significant campaigns Alzheimer Scotland has undertaken. This is a long-term campaign and therefore we are currently continuing to build both support and consensus among key organisations and stakeholders. A crucial element of the campaign is building public and political support for the campaign though a targeted social media campaign and engagement with supporters and key stakeholder groups and organisations at local and national level.

What has been the reaction to the findings within the report – both amongst organisation and amongst people living with dementia?

The report has been received very positively and welcomed by other key stakeholder organisations and professional bodies in Scotland. The Scottish Cross Party Group on Dementia has also welcomed the report and the Convenor MSP Richard Lyle has submitted a motion which will be debated in the Scottish Parliament on the 4 June 2019. The Scottish Government have acknowledged the publication of the report and are currently considering its findings and recommendations.

What are the next steps in the campaign?

We are asking each of the main Scottish political parties to include a commitment to deliver the recommendations of the report in their election manifestos for the Scottish Parliament elections in May 2021. To achieve that we are continuing to build public support so that supporters and our local active voice networks, across Scotland can ask their political representatives to support the Fair Dementia care campaign.

This campaign sits alongside the Alzheimer Scotland’s current vision for transforming the lives of people with dementia and their carers throughout the illness from diagnosis to end of life and in every setting. Whilst we understand that it will require significant effort and dedication to fully transform our system, we have asked that the Scottish Government lead the way by accepting the definitions and recommendations in this report and commit to starting the journey towards delivering fair dementia care for those with advanced dementia in Scotland.

Profile

James Pearson is Alzheimer Scotland’s Director of Policy & Research and is responsible for Alzheimer Scotland’s public policy engagement. He has a background in welfare rights and a particular interest in promoting as well as protecting the rights of people living with dementia.

Jim has an MBA from Glasgow Caledonian University and joined the Board of Alzheimer Europe in 2014, currently serving as Honorary Secretary.

www.alzscot.org
What does accessibility mean for people with cognitive disabilities?

Petri Lampinen, member of the European Working Group of People with Dementia and of Finland’s national working group the “Memory Activists”, discusses accessibility for people with dementia and shares his thoughts on the EU disability card scheme.

People with cognitive impairments should be listened to, regarding the accessibility of products and services. Their feedback should be gathered at the design stage. People with normal cognitive functioning cannot understand the different kinds of challenges that a disease can bring with it. Openness when talking about these matters is for the common good, which is why I want to share my thoughts and experiences with you.

The disease has been an eye-opener for me. Now, I am more aware of the different difficulties that many older or disabled people encounter. Facing cognitive constraints in your daily life makes you think about the importance of accessibility.

Accessibility is often associated with people with reduced mobility or sensory disabilities, but we should also consider how much cognitive difficulties can complicate life. As a person with dementia, I have encountered these difficulties for a few years. Luckily, I have not allowed them to defeat me, and in spite of them, I have managed to continue to live a participatory life.

To support my daily life at home, I started to use a big whiteboard a couple of years ago. I use many colours and eye-catching magnets on it. This has helped a lot to cope at home. It also helps the people close to me feel more secure in the knowledge that I can cope better, especially when I am home alone.

Difficulties encountered outside are often more challenging to manage. Sometimes, my days can be very challenging, as I tend to lose things, be absent-minded and have difficulties with perception of time. Fortunately, I manage to overcome these challenges by staying calm. If I were to give in to fear, I would just stay at home, alone. That would be bad for me, not to mention the people close to me.

These are some of the difficulties I encounter:

Transport difficulties

As a person with dementia, I am lucky to have received services based on a severe disability and have a continuing right to the use of a taxi to access the social insurance institution of Finland and disability services. This system was working well for me for a few years, but now these services are not working. I can no longer contact the driver directly, as all journeys are reserved via a call centre. The flexibility has gone.

Signage and usability of facilities

When visiting shopping centres and other locations, I have noticed the importance of proper signage. Often, signs are out of sight, colourless, too small or hard to understand. When necessary, I have asked for help and have spoken openly about my condition. As a result, I have received support and understanding. Sometimes, I have seen somebody else in a similar situation and helped them, in spite of my disease. That has put me in a good mood. People with dementia can also be dementia-friendly.

Toilet signage should be easier to understand, as well. That would help with using the right facilities. Once, I accidentally went to the women’s toilets in a hospital, which really upset one woman. I took it in good humour, but I am not sure whether everyone would.

Fortunately, I manage to overcome these challenges by staying calm. If I were to give in to fear, I would just stay at home, alone."

I also find most washbasin taps are difficult to use, as the design is too complex. Design is often put before usability.

At airports, I have noticed an improvement in colours and readability of signs, but the announcements could be better. Many times one cannot hear what they say for all the noises around.
Thanks to the card, I have had access to priority boarding, which helps because hustle and bustle and being rushed causes me problems when travelling.”

Packaging

I would like more colour to be used in product packaging, so that they would differ more from each other. Pharmaceutical packs are too similar. Once, I nearly brushed my teeth with insecticide as the package was too similar to the toothpaste pack.

Checkouts

When shopping, I need a little bit more time at the checkout. Some customers look for a quick checkout, I look for a slow one. That is how I can manage my shopping without making mistakes because of being rushed.

Noise and intrusion on personal space

Often, the music is too loud in shopping centres, which disturbs my concentration. I have faced that problem quite often. Especially if I am trying to speak to someone at the time. Certain kinds of intrusive sales in shopping aisles puzzle me. Vendors are often too invasive and I cannot read my list in peace. This disturbs my concentration and irritates me a lot sometimes. I am sure I am not alone in that.

Strong scents

I avoid shops that have strong scents. Fortunately, many people already know to avoid excessive use of scents, but occasionally I come across a place with lots of strong scents and I leave immediately.

Websites and apps

I use many web applications when I travel and they function very well. By using the applications, I can pay and plan my route in advance. I can also follow my route in real time. However, I experience digital distraction when a web page has moving or changing pictures. Pop-up chat windows also hinder my concentration. Sometimes, I have to cover them up with a piece of paper so that I can concentrate better on what I am doing.

What is an EU Disability Card?

Currently, there is no mutual recognition of disability status between EU Member States, which can make things difficult for persons with disabilities travelling to other EU countries. For instance, their national disability cards might not be recognised. To help people with disabilities travel more easily between EU countries, the EU is developing a system of mutual recognition based on an EU Disability Card.

The card will ensure an equal access to certain specific benefits, mainly in the areas of culture, leisure, sport and transport. It will be mutually recognised between EU countries participating in the system, on a voluntary basis.

A pilot programme, prepared with a dedicated Project Working Group composed of 17 Member States and civil society organisations (a sub-section of the High Level Group on Disability), is currently running in a first group of eight EU countries: Belgium, Cyprus, Estonia, Finland, Italy, Malta, Slovenia and Romania. These countries were selected following a call for proposals to support national projects on a mutually recognised European Disability Card and associated benefits.

The Card does not change national eligibility criteria or rules. Member States retain their discretion to decide who is eligible to receive the Card, using the national definition of disability, and to determine the issuing procedure.

Find out more, here: www.bit.ly/EUDisabilityCard

My EU Disability Card

I have been using an EU Disability Card for about a year now and have been very happy with it. I have used it at airports. Thanks to the card, I have had access to priority boarding, which helps because hustle and bustle and being rushed causes me problems when travelling. I keep my disability card ready to show at security too, to avoid difficulties.

Another good point has been that the card includes a symbol showing the need for assistance. If I need help, it is always close at hand.

Profile

Petri Lampinen has been a member of the European Working Group of People with Dementia since 2017, when he was nominated by the Alzheimer Society of Finland (Muistiliitto). He is also a member of the Finnish dementia working group, called the “Memory Activists”.

Petri Lampinen
French families hit hard by government’s decision to stop reimbursing anti-dementia drugs

Joël Jaouen, President of France Alzheimer shares the results of a national survey his organisation conducted, after the reimbursement of these drugs was halted.

In 2018, the French Government took the decision to stop reimbursing the four anti-dementia drugs currently approved in Europe. Since then, France Alzheimer has repeatedly raised the alarm, drawing attention to the growing distress caused to the 3 million families affected. To ensure their voices and experiences are heard, the organisation conducted a national survey.

Since the French Government took the decision to stop reimbursing the four anti-dementia drugs currently approved in Europe, in mid-2018, what action has France Alzheimer taken on behalf of the 3 million families affected and what has been the impact of this action?

First of all, as soon as the delisting was announced, France Alzheimer collected almost 30,000 signatures for a petition online, denouncing the decision.

Then, in July 2018, the organisation decided to appeal to the Conseil d’État (French Council of State), together with seven other medical associations, in the hope that they would overturn the government decision. We are still waiting for the final ruling.

Finally, we launched a national survey among people who are on the front line: people with dementia and their caregivers. The survey gathered more than 2,500 responses. We published the main results, in February 2019.

The survey results published by France Alzheimer clearly show that families have been hit hard by the decision. An earlier ODOXA survey (results published late 2018) also showed that the French public overwhelmingly disagreed with this decision. Has the Government responded to any of these survey results, or to any of the actions taken by France Alzheimer?

Regarding our survey, at this time, we have not had any reaction from the French Government, which is aware of the results. We know that the Government waited for the release of the new report on Alzheimer’s disease, from the Haute Autorité de Santé (HAS) to make the announcement (HAS – High Authority of Health – is the French authority that provides recommendations, especially with regards to the reimbursement of medicinal products).

As part of the French Plan for neurodegenerative disorders, the government had previously promised many times that the delisting would not be announced without first reinforcing the current measures dedicated to the support of people with dementia and their caregivers. Unfortunately, we are still waiting for these measures!

“The government had previously promised many times that the delisting would not be announced without first reinforcing the current measures dedicated to the support of people with dementia and their caregivers. Unfortunately, we are still waiting for these measures!”
While this governmental decision has evidently has a hugely negative impact on many families and has been very badly received by the public, is there perhaps some positive news you can share, concerning care or research? Has the French Government committed to take any positive action in those areas, for example?

The French government said that they would invest more in the field of Alzheimer’s disease. Indeed, the French Plan for neurodegenerative disorders is still running until the end of the year and the main concern of France Alzheimer right now is to make sure that a specific plan will be implemented after 2019, to meet the specific needs of people with dementia and their caregivers, in the long term. For our part, we are still committed to support research, as we are the largest private charity funder of research in France.

Is France Alzheimer planning to take further action in the quest to reinstate the reimbursement of these medications? If so, what can readers do to support this action?

We have now decided to support a clinical trial for which the main objective is to evaluate the efficacy of donepezil in people with Alzheimer’s disease. It will start during 2019. All our actions have been fuelled by the thousands of testimonies of people directly affected by this decision. That is the main reason we keep on fighting to reinstate the reimbursement of anti-dementia drugs. Our energy is now focused on the result of our appeal to the French Council of State, which we hope will be on the side of the millions of people affected by Alzheimer’s and related diseases.

The French Plan for neurodegenerative disorders is still running until the end of the year and the main concern of France Alzheimer right now is to make sure that a specific plan will be implemented after 2019, to meet the specific needs of people with dementia and their caregivers, in the long term.”

Joël Jaouen has been the President of France Alzheimer since June 2015.

He originally started his volunteering activities in the French association by becoming President of one of the 99 local organisations in its network – in Brittany. Fully committed to the cause, his energy comes mainly from his experience as his father’s main caregiver for many years.

www.francealzheimer.org

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Finland holds first ever Memory Parliament

Memory-friendliness was on the agenda of the first ever “Memory Parliament” held in Finland on 13 February 2019. The Parliament gave people with memory-related diseases and their family members the chance to ask Members of the Finnish Parliament questions.

The idea for the Memory Parliament came from Finland’s national working group of people with memory diseases and caregivers.

“They wanted to be heard directly at the decision-making level”, said Anna Tamminen, Director of the Alzheimer Society of Finland (Muistiliitto). “It is important that people with memory diseases can influence decision-making personally”, she continued.

The President of the Alzheimer Society of Finland’s Board, Member of Parliament (MP) Merja Mäkisalo-Ropponen liked the idea and started to organise event, together with the Finnish Parliament’s “Memory Club”. It is open to everyone who works at the Parliament or in parliamentary groups.

A successful event

The Memory Parliament was held in The Finnish Parliament Annex. The event attracted a lot of interest and space filled up quickly.

The Minister of Family Affairs and Social Services, Annika Saarikko gave the opening speech. She highlighted the importance of recent discussions in Finland about the quality of care for older people:

“We have to listen to people with memory-related issues when discussing their care”, she said.

Several lectures covering different issues about memory-friendliness in Finland were also given. There was a panel of four members of the Finnish Parliament, all from different political parties. The audience was able to ask them questions directly. They wanted to know, for example, about support for children with a parent who has an early-onset memory-related disease, and how support and services could be provided equally, in all parts of Finland.

“Everyone involved with the Memory Parliament thought it was a success. We are hoping to continue them in the future”, Anna Tamminen said.

Ms Suomu hopes to meet more of her European colleagues in the near future and looks forward to collaborating with them.
Our members are helping people with dementia and their carers in 37 countries

- ALBANIA – TIRANA
  Alzheimer Albania

- AUSTRIA – VIENNA
  Alzheimer Austria

- BELGIUM – BRUSSELS
  Ligue Nationale Alzheimer

- BOSNIA & HERZEGOVINA – SARAJEVO
  Udruženje AiR

- BULGARIA – SOFIA
  Alzheimer Bulgaria

- BULGARIA – VARNA
  Foundation Compassion Alzheimer

- CROATIA – ZAGREB
  Alzheimer Croatia

- CYPRUS – LARNACA
  Pancyprian Alzheimer Association

- CZECH REPUBLIC – PRAGUE
  Czech Alzheimer's Society

- DENMARK – HELLERUP
  Alzheimerforeningen

- ESTONIA – TALLINN
  NGO Living with Dementia

- FINLAND – HELSINKI
  Maastiliitto

- FRANCE – PARIS
  Association France Alzheimer

- GERMANY – BERLIN
  Deutsche Alzheimer Gesellschaft e.V

- GREECE – THESSALONIKI
  Panhellenic Federation of Alzheimer’s Disease and Related Disorders

- HUNGARY – BUDAPEST
  Social Cluster Association

- ICELAND – REYKJAVIK
  Alzheimer Iceland

- IRELAND – DUBLIN
  The Alzheimer Society of Ireland

- ISRAEL – RAMAT GAN
  EMDA – The Alzheimer’s Association of Israel

- ITALY – MILAN
  Federazione Alzheimer Italia

- ITALY – ROME
  Alzheimer Uniti Onlus

- JERSEY – ST HELENS
  Jersey Alzheimer's Association

- LUXEMBOURG – LUXEMBOURG
  Association Luxembourg Alzheimer

- MALTA – MSIDA
  Malta Dementia Society

- MONACO – MONTE-CARLO
  AMPA – Association Monégasque pour la recherche sur la maladie d’Alzheimer

- MONTENEGRO – PODGORICA
  NVO Futura

- NETHERLANDS – AMERSFOORT
  Alzheimer Nederland

- NORWAY – OSLO
  Nasjonalforeningen Demensforbundet

- POLAND – WARSAW
  Polish Alzheimer’s Association

- PORTUGAL – LISBON
  Alzheimer Portugal

- ROMANIA – BUCHAREST
  Societatea Alzheimer

- SLOVAKIA – BRATISLAVA
  Slovak Alzheimer’s Society

- SLOVENIA – LJUBLJANA
  EMDA – The Alzheimer’s Association

- SPAIN – MADRID
  Fundación Alzheimer España

- SPAIN – PAMPLONA
  C.E.A.F.A.

- SWEDEN – LUND
  Alzheimer Sverige

- SWEDEN – STOCKHOLM
  Demensförbundet

- SWITZERLAND – BERN
  Association Alzheimer Suisse

- TURKEY – ISTANBUL
  Alzheimer Vakfı

- UNITED KINGDOM – EDINBURGH
  Alzheimer Scotland

- UNITED KINGDOM – LONDON
  Alzheimer’s Society