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Cabinet Secretary for Health and Social Services talks about the new Dementia Action Plan for Wales

Françoise Grossetête
discusses the future of the European Commission’s health programme

Carey Mulligan
talks about her role as a global dementia friends ambassador

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addresses importance of EU action on dementia prevention
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I am pleased to welcome you to the 27th edition of our Dementia in Europe magazine, the second edition this year and with a brand new design and layout. We hope you enjoy reading it as much as we do.

Alzheimer Europe is committed to making Alzheimer’s disease a European priority. This edition showcases much of the work done not only by Alzheimer Europe at European level but also by our member organisations at national level.

The first section highlights some of Alzheimer Europe’s activities. The recent lunch debate in the European Parliament focused on the prevention of Alzheimer’s disease looking at a number of key projects and initiatives funded at an EU level to identify interventions and therapies to delay or prevent dementia. I would like to thank the MEPs Heinz K. Becker (Austria), Deirdre Clune (Ireland), Marian Harrkin (Ireland), Rory Palmer (UK) and Keith Taylor (UK) who attended the lunch debate for their active participation and excellent questions.

I would also like to express my thanks to the experts working closely with the Alzheimer Europe team who updated policy makers and our organisations about ongoing research. As a convinced European, I was impressed by the collaboration at EU level to address the challenge of dementia.

Alzheimer Europe’s close involvement and collaboration in successful European projects is another area of work I am very proud of. In this edition of the magazine we take a look at the EMIF (European Medical Information Framework) project which has been very successful at accessing volumes of healthcare data to accelerate research in Alzheimer’s disease. The second project we take a look at is the PRODEMOS (Prevention of dementia using mobile phone applications) project which was launched in January this year.

The number of European countries with a national dementia strategy continues to grow and we have an interview with Vaughan Gething, Cabinet Secretary for Health and Social Services on the new Welsh dementia strategy launched in February. To mark the mid-term of the dementia strategy in Luxembourg, our colleagues from the Alzheimer Association of Luxembourg update us on their involvement in the implementation of the strategy including the Dementia prevention programme the new “Info Zenter Demenz” and recommendations on dementia in hospital.

I am delighted to bring you the news that Ireland has finally ratified the United Nation Convention on the Rights of Persons with Disabilities (UNCRPD). Ireland is the last of the EU Member States to ratify the UNCRPD and the Alzheimer Society of Ireland shares how this will have a positive impact on the rights of people living with dementia.

It is difficult not to mention Brexit in European discussions these days and Colin Capper from the UK Alzheimer’s Society talks about the effect of Brexit for people with dementia. We also update readers on the new general data protection regulation which came into force in May and the implications for health data and for people with dementia.

The European Alzheimer’s Alliance continues to be active and we are pleased to have an interview with the Chairperson Françoise Grossetête, MEP (France) on the future of the Health Programme. We are also pleased to report that Deirdre Clune, MEP (Ireland) who is a member of the European Alzheimer’s Alliance addressed a Written Question to the Commission asking why the Government Expert Group on Dementia was disbanded.

In the Dementia in Society section we are pleased to have an interview with the actress Carey Mulligan from the UK who writes about being a Global Dementia Friends Ambassador. Nationally, we look at the Demenca aCROSsLO cross border project with collaboration on dementia between Croatia and Slovenia. From Finland’s Memory Activists, we hear about their involvement in the development of palliative care, terminal care and euthanasia and globally we see what the World Rocks Against Dementia (WRAD) festival is all about.

Our look at the real story behind the media headlines for this edition is on whether we are close to having a blood biomarker for dementia diagnosis.

I would like to wish you all a very happy summer and we will be back in October with the third and final edition of 2018 with a special section on the Alzheimer Europe Annual Conference which will be held in Barcelona from 29–31 October 2018.

Happy reading!
Alzheimer Europe holds successful European Parliament lunch debate

The lunch debate focused on the potential for interventions in the earlier stages of dementia and dementia prevention.

On 27 February Alzheimer Europe (AE) held a successful lunch debate in the European Parliament which focused on the prevention of Alzheimer’s disease (AD) and dementia. The lunch debate gathered over 50 people including MEPs Heinz K. Becker (Austria), Deirdre Clune (Ireland), Marian Harkin (Ireland), Rory Palmer (UK) and Keith Taylor (UK). The audience included representatives from 20 Alzheimer Europe member associations and several pharmaceutical companies.

Iva Holmerová, Chairperson of Alzheimer Europe opened the debate and welcomed all participants. The lunch debate looked at the potential for interventions in the earlier stages of dementia and dementia prevention. Europe is already financing several key research initiatives in this area illustrating the importance of EU research programmes to address this promising field of dementia prevention.

Europe is already financing several key research initiatives in this area illustrating the importance of EU research programmes to address this promising field of dementia prevention. During the discussion the speakers looked at social innovation, modifiable risk factors through nutrition, physical exercise, blood pressure and cholesterol control etc. as well as the development of pharmacological interventions working on the underlying brain processes.

**Promoting long term brain health and prevention**

The first speaker, Kate Irving, Professor of Clinical Nursing at Dublin City University, Ireland spoke about reducing dementia risk by targeting modifiable risk factors in mid-life and the lessons of the In-MINDD project which promotes long term brain health and prevention to at least delay the onset of dementia.

Prof. Irving started by talking about her own personal lived experience with dementia as she cares for her mother who has moderate to mild dementia and her personal message was that she is really hopeful there will be a lot more understanding of dementia during the next few decades but for this to happen we need to engage in a lifespan approach to interventions not just theoretical targets.

Prof. Irving also pointed out that compared with other diseases, dementia research is vastly underfunded and the success rate of clinical trials into dementia is very low. Prof Irving stressed the need for better balance in research and the need for a broader understanding of the disease. She believes that there needs to be a trickledown effect to individuals to address the questions about how we engage people in thinking and talking about dementia and its prevention at primary, secondary and tertiary level.

Prof. Irving said it is possible to prevent one third of the cases of dementia but there is very poor knowledge amongst the general public about what can be done due to the poor visibility of dementia prevention in public health policies.

Prof. Irving welcomed the recent work of the World Health Organisation (WHO) which is incredibly helpful in declaring dementia a public health priority. However, even though dementia prevention is “coming of age” it still remains the poor relation in the non-communicable diseases (NCD) group.

**Targeting modifiable risk factors**

The second speaker was Edo Richard, Neurologist at the Academic Medical Centre, Amsterdam and Radboud University Medical Centre, Nijmegen, Netherlands from the European Dementia Prevention Initiative (EDPI) a project connecting European researchers who perform dementia prevention research. Dr Richard started by talking about the expected increase of prevalence of dementia over the next decade but, as the world is constantly changing, risk factor knowledge from the last decades is perhaps now partially outdated and actual risk factors for dementia have changed.

However, 30% of all dementia cases can be attributed to 7 potentially modifiable risk factors: diabetes, hypertension, obesity, inactivity, depression, smoking and low education. Dr Richard said that we know about heart disease and cardiovascular disease and we have more knowledge of smoking and its dangers but new risk factors such as those associated with diabetes for example have risen and we need to start to look at these areas.

Dr Richard agreed with Prof Irving in saying that if we treat risk factors it has to be across the life span. He explained that several research groups have looked at what would happen if...
we treat a combination of risk factors at the same time, as all risk factors interact. Since prevalence is expected to rise most dramatically in lower and middle income countries, any intervention strategy has to be affordable and widely applicable across a variety of healthcare settings.

For example, Dr Richard said that if we could reduce risk factors by 10%, by 2050 there could be a theoretical reduction of dementia by 8% (about 8 million people). If people engage in healthy lifestyles such as diet and exercise, then risk factors will be reduced however in practise this is much more difficult to implement. He highlighted how this can possibly be done through the use of eHealth, as currently investigated in the “Healthy Ageing Through Internet Counselling in the Elderly” (HATICE) project.

Dr Richard summarised by saying that the key to addressing dementia prevention is from a population perspective. At the end of the day by modifying risk factors we should be able to shorten the period that people live with cognitive impairment.

### Dementia prevention

The final speaker was Prof. Craig Ritchie from the European Prevention of Alzheimer’s Disease (EPAD) IMI project who looked at what the project can offer in terms of research into prevention. EPAD is about creating a novel environment for testing numerous interventions (drugs and non-pharmacological interventions) targeted at the prevention of Alzheimer’s dementia.

Prof. Ritchie said that preventing dementia is feasible but the problem is that dementia is only really diagnosed post mortem. However, more recent research has shown that pathology develops much earlier in a brain even before symptoms of dementia appear. To get a better idea of how dementia develops we must first understand in much more detail the neurodegenerative disease mechanisms and how they present clinically decades before dementia develops then secondly map interventions onto these mechanisms either through risk modification or targeted pharmacology. This is where the EPAD project will help deliver on those objectives.

### Useful data

EPAD also offers the gift of data as people will enrol into the study and it will be possible to observe how the disease progresses over time and identify a multitude of other effects on brain failure. Prof. Ritchie talked about clinical trials and the failure rate, he stated that one of the reasons for the failure rate could be that we are not taking time to look at the earlier phases of the disease and the build-up of pathologies before dementia symptoms appear. Again this is an area targeted by the EPAD project.

Prof. Ritchie said that the goal of EPAD is to have an algorithm that can apply to any single individual including modifiable and non-modifiable risk factors, cognition and biomarkers.

### Causes of dementia

A lively discussion and question and answer session followed the speakers. Keith Taylor, MEP raised the point about whether pollution could be a cause of dementia, stating...
that metal transport generated particles have been found in the brain post mortem. Considering this is responsible for so many other diseases including cardiovascular disease which in itself is a risk factor for dementia, he wondered what the link to dementia was. Prof. Richards responded saying it is difficult to interpret results in relation to dementia and to establish a direct relation between pollution and dementia. Whilst there were associations between the two, it was difficult to establish causal links.

Prevalence

Marian Harkin, MEP raised three very relevant points. Firstly by asking if there were any populations with low or lower than average prevalence; secondly whether the increase of dementia is in parallel with ageing or is the rate of dementia increasing faster and thirdly she wanted to know how a combination of risk factors affected a person’s risk. Prof. Ritchie responded that we do not have answers to all these questions yet and that we would need more monitoring and research to better understand the prevalence of dementia in different populations and how cumulative risk factors affected overall risk.

Jean Georges, Executive Director of Alzheimer Europe thanked the speakers and wondered whether they had any advice on how to improve the inclusion of dementia in non-communicable disease strategies at European and national level. Prof. Richard suggested using the messaging from risk factors on cardiovascular disease in terms of the prevention of dementia.

Jayne Goodrick, supporter of Chris Roberts (European Working Group of People with Dementia) stated that at grassroots level for those living with dementia, more education of primary physicians and GPs is needed. Prof. Irving agreed and said that we need to reduce the fear in society by having a broader definition of dementia to counterbalance the general public feeling of hopelessness of developing a disease with little hope for a cure.

So much more work to be done on prevention and in research

All speakers agreed that more could and should be done in the area of prevention. Currently there is a much higher focus on basic research and clinical research but research should start to focus more on prevention. Just confining dementia as a medical disease is too limiting because if it is defined as more than just the neurological impairment then maybe there are things everybody can do to prevent it.

Iva Holmerová, Chairperson of Alzheimer Europe, announced the publication of AE’s two new publications, the 2017 Yearbook on “Care standards for residential care facilities in Europe” and the Ethics report on “Dementia as a disability?” Iva Holmerová then thanked everybody for coming and the AE corporate sponsors of the event, Lilly, MSD and Roche.

The next AE European Parliament lunch debate will be on 26 June 2018 and will be entitled “Dementia Care in the European Union”.

“Thirty percent of all dementia cases can be attributed to 7 potentially modifiable risk factors: diabetes, hypertension, obesity, inactivity, depression, smoking and low education”

Edo Richard
MEPs speak out on Alzheimer’s disease

Alzheimer Europe asked MEPs who attended the lunch debate: What can be done at European level to ensure dementia prevention is included in strategies and policies for non-communicable disease and how can the EU support awareness campaigns on modifiable risk factors of dementia?

Rory Palmer (UK)

There is much political will to secure better dementia prevention across the European Union – social challenges of this size and scale require cooperation across international borders. Whether it’s working together on research, sharing information about different trials and strategies that are being used at a national level, or using our political leverage to drive up standards and protections across Europe, it is clear that increased cooperation across the EU offers a pathway towards preventing dementia.

As politicians, our challenge is to relentlessly push dementia up the political agenda. That means working within our parties and groups to influence manifestos, getting more MEPs to engage with dementia as an issue and making sure that we focus on the human side of dementia – the statistics are alarming, but its raising awareness of the human cost that will really drive change.

From a UK perspective the Government must make sure that the UK continues to be a part of these conversations after 2019. After all, the UK’s departure from the EU does not affect the ticking dementia time bomb that we face across Europe, and just because the UK is leaving the EU does not mean that we should not work together where we can to improve the health and lives of people across the continent.

Deirdre Clune (Ireland)

The number of people with dementia has tripled since 1950 and today’s numbers are expected to double every 20 years according to the World Health Organisation (WHO). Europe is certain to bear a disproportionate amount of this growth as a result of our ageing population. It is vital that we work together to share best practice, pool resources and especially share relevant data, if we are to help today’s and future generations benefit from best practice.

In the EU, healthcare is considered a matter for Member States. It us up to national governments to organise health systems which can best care for and protect citizens. However, the EU can play a role in complementing national policies by helping governments achieve shared objectives. I believe that a lot can be done at the EU level to help Member States tackle the challenge that dementia poses. There is a large amount of information held by carers and medics in daily contact with dementia patients that could be shared across all Member States to ensure best practice occurs or has been developed.

Pharmaceutical companies continue to focus on developing a breakthrough, but despite much work, there is still no medical cure for dementia. However, I am confident in the capabilities of science. European research programmes such as Neurodegenerative Disease Research provide data and support for new treatments which will alter the course, and improve the quality of life for those with dementia. The programme aims to increase and coordinate investment between countries participating in this area focusing on cures, and appropriate care paths for those with a diagnosis.

I believe the EU can play a strong role in the coordination of best practice in all Member States, in order to guarantee an improved quality of life for all involved.
Snapshots from Alzheimer Europe’s European Parliament lunch debate
Alzheimer Europe is involved in a new collaborative initiative to develop a mobile health application to prevent dementia

The PRODEMOS project aims to make an evidence-based dementia prevention strategy using mobile health accessible to those at increased risk of dementia who are usually not reached by preventive medicine

The prevention of dementia using mobile phone applications (PRODEMOS) project announced the start of a novel research initiative during a kick-off meeting on 15–16 January 2018 in Amsterdam (Netherlands).

PRODEMOS aims to make an evidence-based dementia prevention strategy using mobile Health accessible to those at increased risk of dementia who are usually not reached by preventive medicine. From a global perspective, the project will target socio-economically deprived populations in the EU and a population at risk of dementia in China. The final aim is to implement this flexible fully adaptable mHealth platform in a culturally appropriate form in a range of health care settings across the globe.

The project has a duration of five years and an initial budget of around EUR 3 million distributed across a total of eight partners from the private and academic sectors:

- The Chancellor, Masters and Scholars of the University of Cambridge, UK
- Capital Medical University, China
- Vitalhealth Software BV, The Netherlands
- Karolinska Institutet, Sweden
- Institut national de la santé et de la recherche médicale, France
- The University of Manchester, UK
- Alzheimer Europe, Luxembourg

In this project, Alzheimer Europe will be representing the patient perspective. Alzheimer Europe is also involved in the coordination and management, crossing cultural barriers and dissemination and communication work packages of this project.

This project has received funding from the European Union’s Horizon 2020 research and innovation programme under grant agreement No 779238.
Eric Moll van Charante and Edo Richard, the two project co-coordinators, present the overall vision of PRODEMOS

**What issues are you aiming to address with the PRODEMOS project?**

Our aim is to investigate if we can prevent dementia using a mobile phone application. The application will help users improve their lifestyle and reduce their risk of dementia. We explicitly focus on those at increased risk of dementia, who are currently insufficiently reached by preventive health care. In our project this is embodied by persons with low socio-economic status in the European Union and people in China. We have chosen China, because in this middle-income country, the prevalence of dementia is expected to rise sharply due to the higher life-expectancy, but also the growing unhealthy lifestyles that accompanies increasing prosperity.

**What are the concrete objectives and actions which will be undertaken by PRODEMOS?**

1. We will explore attitudes of the target population towards dementia prevention and the use of mobile health for this purpose; we will pay careful attention to cultural aspects in different target populations;

2. We will develop a culturally appropriate mHealth platform, based on our previously developed eHealth platform, for self-management of dementia risk factors;

3. We will perform a large randomised controlled trial in the UK and China to evaluate the feasibility and effectiveness of this intervention;

4. With these objectives, we prepare for large-scale implementation of a dementia prevention intervention using a mobile Health application.

**What are the benefits of delivering a mobile health application to those at increased risk of dementia?**

Those at increased risk often don’t have proper access to current preventive medicine. Particularly in low- and middle-income countries, alternative ways of delivering preventive health care are urgently needed. The use of smartphones is increasing rapidly across the globe. Where saturation is almost reached in some European countries, in many middle-income countries there is a sharp rise in smartphone possession and use. This offers great opportunities to reach large numbers of people at relatively low costs. Traditional contacts with health care providers are not everywhere possible, but in the near future most people will be reachable by smartphone.

**“ Our aim is to investigate if we can prevent dementia using a mobile phone application”**

**What are your expectations from and hopes for the project?**

We expect that there will be major cultural differences in the way people in China and the EU look at dementia, its prevention, and the use of mHealth for this purpose. We expect that the European mHealth platform will function very differently from the Chinese platform, with different approaches towards prevention of dementia. The results of the randomised controlled implementation trial will hopefully show that this method of delivery of a dementia prevention strategy is feasible and that the use and uptake by participants will be high. If the results also show that the risk of dementia is indeed reduced by this strategy, we expect to start an even larger and longer study to evaluate the long-term effects on actual cognitive functioning and the occurrence of dementia. Finally we expect that the collaboration with China will teach us more about ways to approach dementia prevention from a global perspective. This is essential, because the largest increase in dementia will be in low and middle-income countries in the coming decades.

**About PRODEMOS**

PRODEMOS project aims to make an evidence-based dementia prevention strategy using mobile Health accessible to those at increased risk of dementia who are usually not reached by preventive medicine.

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Particularly in low- and middle-income countries, alternative ways of delivering preventive health care are urgently needed”
The European Medical Information Framework (EMIF) project improves access and use of health data

Jelle Praet, Project Manager, illustrates how the EMIF project lives up to its ambition of providing and enabling access to an unprecedented volume of healthcare data and accelerating research in the field of Alzheimer’s disease

Despite increased recognition of the enormity of the unmet medical need represented by Alzheimer’s disease, and the increased funding to research that has followed this in recent years, we still have no therapy for the disease itself. Progress has been made, for example, in understanding the disease and in the search for biomarkers – but it is too little, too slow and with no translation to successful clinical trials. Clearly we cannot continue as we are. ‘Steady as you go’ is not a good course of action when facing the growing crisis of Alzheimer’s disease and other dementias in our ageing populations.

Generating new ideas

So what might we do that is different? What might help to generate new ideas for therapies, new evidence for mechanisms and better biomarkers than we have today? Might ‘data’ be the answer, or at least part of it? EMIF was set up with the perspective that enabling better access to data for the scientific community is indeed an opportunity to accelerate research into dementia and other disorders.

The premise of EMIF is that the vast amount of data that could accelerate medical research is not widely visible to scientists, accessing it, is often complicated and combining data from one source with that from another even more so. EMIF set out to rectify this, making data findable, accessible, inter-operable and reusable, a process known as FAIR-ification.

We have done this with two types of data. Firstly with cohort studies of volunteers in studies often including people with dementia, people without dementia and people with mild memory problems. There are large numbers of such cohorts and EMIF has included studies with over 60,000 participants and growing. The second data type that we are working with is routine clinical care – all of that information collected when you see your family doctor or get treated in hospital. Here EMIF is working with medical records systems holding over 60 million medical records.

The challenges of making data accessible

Clearly, making such data accessible to researchers in their quest to create therapies for Alzheimer’s disease involves a number of challenges. First amongst these is that of information governance and ethics. Here, EMIF has observed the very best and most advanced approaches to ensuring privacy and security. Where a volunteer in a research study has agreed to share the data collected in that study, we do so only when it is fully pseudonymised meaning that a researcher using EMIF cannot access any personally identifiable information. Where the data comes from medical records the data stays with those doctors and hospital systems and a researcher is only allowed to send a research query to that dataset via a trusted third party and is not allowed to see any personal identifying data. Also, each application to research the data is thoroughly judged for scientific and ethical acceptability.

Beyond ethical issues, there are many technical hurdles to overcome. EMIF has brought some of the best scientists in the field to tackle these and we are delighted that we have made such progress over the last 5 years. Our teams have, for example made catalogues of the data sources that allow scientists to find the data they need for their work and processes to harmonise data that allows it to be brought together from many different sources and used for better, more effective research.

A blood biomarker?

To tackle that problem EMIF researchers sought to collect blood samples from people who have had the spinal fluid or PET imaging tests, and look for a blood marker. To do this from scratch would take very many years and very many millions of euros. But using the EMIF tools the researchers were able to find and access the right data and right study volunteers and work with studies again from all over Europe to gather samples already collected. Analysis of those samples is ongoing but looks very promising that a biomarker to make clinical trials more effective will be found.

These are just two very different examples. In total over 60 scientific publications have been produced using the resources established by EMIF. This is an extraordinary achievement and this work is already adding to our understanding of the disease, finding biomarkers, proposing new therapeutic avenues and speeding clinical trials. It’s a testament to the excellence of the teams working on the project, the willingness of scientists from across Europe to collaborate and most of all to the power of re-using data, respectfully and appropriately, to make research into finding better treatments and perhaps even a prevention for Alzheimer’s disease and other dementias.

What might help to generate new ideas for therapies, new evidence for mechanisms and better biomarkers than we have today? Might ‘data’ be the answer, or at least part of it?”
EMIF holds final general assembly meeting and public symposium ‘Liberating evidence from European Health Data’

On 16–17 April the EMIF consortium held its final general assembly meeting in Brussels. In addition to this on 18 April, over 110 people attended the public symposium entitled ‘Liberating evidence from European Health Data’.

Bart Vannieuwenhuyse (Janssen, BE, EFPIA coordinator) and Sir Simon Lovestone (University of Oxford, UK, Academic coordinator) started by reflecting on the very successful journey of EMIF. Since its initial conception in 2011, EMIF has more than lived up to its ambition of providing and enabling access to an unprecedented volume of healthcare data, and to accelerate research in the field of Alzheimer’s Disease (AD). Testimonial to the tremendous success of EMIF are the many publications (EMIF is one of the best cited IMI projects) and the leverage of tools to other projects and communities.

Johannes Streffer (UCB, BE, EFPIA lead of EMIF-AD) and Pieter-Jelle Visser (Maastricht University, Netherlands, Academic lead of EMIF-AD) explained how EMIF-AD has focused heavily on the re-use and enrichment of AD cohort data, which in turn delivered new insights in the pathophysiology of AD and has helped to identify potential new AD biomarkers. Exemplar for this focused effort are the AD cohort catalogue and the enriched EMIF Biomarker discovery cohort. When asked what they would do differently if they were to redo the project, they replied that the political and legal dimensions of working with real world data should not be overlooked, but instead be tackled as soon as possible in future projects.

**EMIF Biomarker discovery study**

Two early-career researchers, Isabelle Bos from Maastricht University, NL and Sarah Westwood from the University of Oxford, UK, presented their work on the EMIF Biomarker discovery study. This study re-uses the data from 1,221 subjects, selected from 14 established Alzheimer’s disease (AD) cohorts. In addition, the available dataset was tremendously enriched by doing a multi-omics study on the available DNA, plasma and cerebrospinal fluid (CSF) samples of these subjects. In doing so, EMIF was able to create a large AD cohort, which outperforms any other cohort in the amount of data collected on each subject. This cohort is a real treasure trove for biomarker research and as the sample analyses are nearing completion, EMIF researchers are eager to analyse the data.

Besides EMIF, many other projects are currently impacting the European health data ecosystem. Nemanja Vaci from the University of Oxford, UK presented how the IMI ROADMAP project tries to develop efficient uses of real world evidence for the benefit of AD patients. Gerald Luscan of Pfizer, France) gave an overview of how the IMI EPAD project is building a platform to accelerate clinical trials, and how participants are being recruited in the EPAD Register. Both ROADMAP and EPAD have leveraged some of the outcomes of EMIF-AD. EPAD for example, has adopted the EMIF Catalogue tool to help build its community of AD cohorts while ROADMAP has initiated the process to re-use data of EMIF Biomarker discovery cohort.

As the General data protection regulation (GDPR) will be effective from the 25th May 2018 onwards (see article on page 26), Nikolaus Forgo from the University of Vienna, Austria) was invited to give the audience a crash course on this new legal framework covering the use of real-world data. Many of the researchers in the audience wondered whether they will still be able to use real-world data under the GDPR. While several things change and the penalties for being in breach with the GDPR will be much higher as before, the GDPR also offers reliefs and new opportunities to allow the use of real world data for research purposes. Equally important to the new GDPR was the discussion on how we can better involve patients in these kinds of projects. Valentina Strammiello from the European Patient Forum, presented the patient’s perspective on the re-use of healthcare data and stressed that while patients are genuinely concerned about data security and privacy issues, they do want bona fide researchers to be able to access their data. Patients want to be involved and to be in control over their own data.
The Welsh Government launches new action plan to help people living with dementia in Wales

Vaughan Gething, Cabinet Secretary for Health and Social Services Wales talks to Alzheimer Europe about the new plan to transform dementia care in Wales and his vision for Wales to be a dementia friendly nation and to ensure people with dementia can live as independently as possible in their communities.

Why does Wales need a dementia strategy? What is the background?

My vision is for Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities.

Over the last three years the Welsh Government has invested in dementia risk reduction programmes, to raise awareness of the lifestyle changes we can all make to reduce our chances of developing dementia. We have invested to improve diagnosis rates by reducing the waiting times for local memory clinics. We have funded dementia link nurse sessions and training for care homes staff. We have also invested in flexible resource teams in district hospitals, occupational therapy support in older persons’ units and dementia support workers in primary care settings.

Our innovative Dementia Action Plan will progress commitments relating to dementia in the Welsh Government’s strategy ‘Taking Wales Forward’ and within ‘Prosperity for All’, setting out the range of stakeholders who can support this agenda and the actions required to make a real change. The Welsh Government have developed this plan with those who know most about what needs to be done to improve truly person-centred dementia services – those with lived experience of dementia, their families and carers and service providers.

The recent independent Parliamentary Review of Health and Social Care in Wales, challenges Wales to move to a seamless system within health and social care and to demonstrate we are doing things differently. I want the delivery of this plan to be an active demonstration that Wales can achieve the vision of the Parliamentary Review, providing services that focus on the needs of the individual and ensuring individuals with dementia are central to planning of services.

From your perspective which of the commitments in the new strategy have priority and what is still the biggest challenge?

To truly embrace our vision for Wales to be a dementia friendly nation we need to take action right across the pathway which is outlined in our plan. However one of the main themes within it is to enable people living with dementia to maintain their...
To develop and deliver this plan, we wanted to start by asking multi-agency Regional Partnership Boards in Wales to take a fundamental look at the existing dementia services and care pathways in their area and develop services in line with the dementia plan which address these gaps. It will be crucial to work with both statutory and voluntary sector agencies as well as people living with dementia and their carers in the delivery of these teams as I want to ensure that the care and support which is offered is genuinely person centred.

How is the strategy being funded? What is its budget for implementation?

To support the delivery plan, I have provided £10m a year from 2018–2019 onwards to begin the steps towards change in support that is needed in this area. During these challenging financial times, this investment is a major commitment and supplements the existing funding across Wales to bring to life the important actions set out within the plan.

Can you explain how important it was for the Welsh Government to include people with dementia, their families and carers in the consultation and development of the strategy?

To develop and deliver this plan, we wanted to work with those who know most about what needs to be done to improve truly person-centred dementia services – those with lived experience of dementia, their families and carers and service providers.

We undertook extensive stakeholder engagement to ensure we developed a plan that focused on the things that mattered to individuals and are grateful to both Alzheimer’s Society Cymru and the Dementia Engagement and Empowerment Project (DEEP) who also used their established mechanisms to engage with their membership. Over 1300 people affected by dementia and stakeholder organisations contributed to the consultation process.

This engagement and feedback was at the heart of the process. We listened to those who told us that the plan needed ‘a rights based approach’; that support needs to be flexible to the different needs at different stages of living with the dementia; and, that action must demonstrate a “whole pathway” approach.

The development of the plan was also supported by a task and finish group, including representation from various areas of Welsh Government and key external stakeholders which included people living with dementia, their families and carers.

How important is the Governments relationship with Alzheimer Society Cymru?

The Welsh Government has worked with Alzheimer Society Cymru over a number of years. The organisation has helped to inform our government policies to improve services, providing advice and challenge. This relationship is important to help focus changes on what matters to those individuals living with dementia.

Is there a need for closer collaboration on dementia at a European and Global level?

Dementia is a global problem, and it is important that partners across the world come together with a common goal and a shared purpose. Only by working together will we have the greatest opportunity to better understand the causes and management of dementia, which will enable the development of new treatment and care approaches.

In Wales, we recognise the importance of international collaboration and have in place a research infrastructure which is well-placed to work across borders. Wales is home to the Centre for Ageing and Dementia Research (CADR), a world class research centre built on internationally recognised and transformative research networks. CADR work themes reflect priority policy areas in Wales, Europe and globally and through close European and International collaborations, CADR contributes to Taking Wales Forward (http://gov.wales/docs/strategies/160920-taking-wales-forward-en.pdf) by providing research to impact on dementia services.

My vision is for Wales to be a dementia friendly nation that recognises the rights of people with dementia to feel valued and to live as independently as possible in their communities.

To support the delivery plan, I have provided £10m a year from 2018–2019 onwards to begin the steps towards change in support that is needed in this area.
The Luxembourg national dementia plan aims to support people with the disease and their families

Luxembourg Alzheimer Association discusses its involvement in the national dementia plan including the Dementia Prevention Programme (pdp), the development of the “Info-Zenter Demenz” and recommendations on dementia in hospital

In recent years, many European countries including Luxembourg have put in place numerous national actions focused on dementia. For the period 2009–2014, the Luxembourgish Ministry of Health and the Ministry of Family and Integration were both responsible for the implementation of a national dementia action plan.

The priorities of the plan include the prevention, early diagnosis and the medical care of people with dementia. The various measures of the dementia action plan put in place, to delay the progression of the disease and to avoid the care dependence as long as possible, are coordinated by the Ministry of Health and include:

- the implementation of a range of secondary prevention
- developing a standard “two-level diagnostic”
- the establishment of national standards for the medical care of patients with dementia.

The Ministry of Family and Integration is focusing its efforts on providing information about the disease to the patients, their families and the general public. Another goal is to establish a specific training programme for staff working in services and institutions for the elderly.

As well as medical responses, the national plan aims to support people with the disease and their families. The goal is to learn how to live better with the disease and to offer people with the disease the opportunity to stay as long as possible in their own homes.

Priorities of the national dementia plan

Initially, a set of specifications was developed around two thematic axes: the improvement of the quality of life of the patients and their carers as well as having an active role in society. To this end, different working groups were developed composed of family members of patients, professionals, ministries, political actors, civil society actors and delegates from various associations such as the “Alzheimer Luxembourg Association” (ALA). At the end of their work, each group submitted a report with proposals for priority actions to the steering committee responsible for drafting the final report.

Proposals

The proposed actions that have been selected and forwarded to the government by the steering committee were classified into seven different categories:

1. “Active ageing”, “ageing in good health”
2. Diagnosis and medical management for the first signs of the disease
3. Accompanying the person concerned and his family
4. Home support
5. Institutional care
6. Ethics and law

Since its opening, the Info-Zenter Demenz has proven that there is a real demand for information about dementia.”

Denis Mancini, Lydie Diederich

Luxembourg Alzheimer Association
When a person with dementia is admitted to hospital, their specific needs are not always well understood and taken into account

Denis Mancini, Lydie Diederich

According to the ALA’s directory: “The national dementia plan has enabled progress in the field with an extremely positive impact. In a short time, it has helped to raise awareness to politicians and the general public. Although a number of measures still need to be put into practice, the national plan is an excellent support for ALA.”

Some measures have been implemented through the national dementia plan such as the Dementia Prevention Programme (pdp), the development of the “Info-Zenter Demenz” and recommendations on dementia in the hospital. ALA has actively contributed to these three achievements.

The “Dementia prevention programme”

The “Dementia prevention programme” (pdp), launched in June 2015 by the Ministry of Health, aims to have a positive impact on the evolution of memory disorders through a set of different preventive measures. It aims to support and advice people with mild memory decline in a holistic way. The decision to involve a patient into the pdp is taken in close collaboration with the GP. Indeed, consented people who are suspected of mild cognitive impairment and who show the signs of an elevated risk factor can be referred by their medical practitioner doctor to the pdp.

As part of the pdp, the patient is carefully examined by a neuropsychologist in order to create a personal cognitive profile by taking specific memory tests. If necessary, additional examinations may be scheduled by their own doctor.

The pdp experts are not only in contact with doctors, but also with local partners for:

- cognitive training
- physical and social activities
- dietary advices
- social assistance.

These local partners, from the medical and non-medical fields (e.g. general practitioners and specialists, hospitals, sports associations, senior clubs, municipalities) offer a wide range of activities that can be useful for the prevention of dementia.

Since its launch, the pdp has experienced a series of conceptual adaptations that have been praised by ALA. This year, it has entered its second phase and is now pursued by the Luxembourg Center for Systems Biomedicine (University of Luxembourg) under the direction of Prof. Dr. Rejko Krüger.

The establishment of the Info-Zenter Demenz

One of the objectives pursued by the national dementia plan has been to establish a neutral structural service responsible to guide and support people with disease and their families. ALA, which has been involved for more than 30 years in helping people with dementia and their loved ones and offers a wide range of services (i.e. listening and support groups, emergency telephone reception, help and home care service), was involved in the development of an information and orientation center. The Info-Zenter Demenz opened its doors in 2016. Located in the heart of the Luxembourg City, this national center provides information on the disease (e.g. leaflets, videos) as well as on the services that can be called following the diagnosis of dementia. It also undertakes awareness-raising actions to break the taboo and make the theme of dementia socially acceptable. “Since its opening, the Info-Zenter Demenz has proven that there is a real demand for information about dementia. Moreover, the offer of the Info-Zenter Demenz completes perfectly our own services”, explain the members of the ALA directorate.

In the meantime, the aim was to make available information and documentation on all forms of dementia and existing care to the general public. As a consequence, the Ministry of Health in consultation with the Ministry of Family have developed and launched the site: demence.lu.

Dementia in the hospital

“When a person with dementia is admitted to hospital, their specific needs are not always well understood and taken into account. At the level of hospital care, it was therefore essential to develop good practices to fill the gaps in the field of knowledge about dementia, improve the exchange of information between providers such as ALA and hospitals, to inform the medical staff about the needs of people with dementia and to propose a systematic screening”, explains the directorate of ALA. “These recommendations must adapt to daily life in hospitals for people with dementia, provide better supervision or even greater involvement of loved ones, to propose suitable nourishment supply to avoid malnutrition and specific training for hospital staff. The recommendations will be available soon through a brochure from the Ministry of Health. Although the executive board of ALA is satisfied with the results already achieved, it states that: “Regarding dementia in the hospital, the theoretical bases have been laid but we are still far from the real implementation in practice. We sincerely hope that hospitals will quickly implement the recommendations recently developed”.

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Lydia Mutsch was born on 17 August 1961 in Dudelange. She studied political and social sciences at the University of Göttingen, graduating in 1985. Following elections in October 2013, she joined the government as Minister of Health, Minister for Equal Opportunities.

www.gouvernement.lu

This year, the Ministry of Health, in cooperation with the Luxembourg Center for Systems Biomedicine (LCSB) and other national partners, has implemented a dementia prevention programme.

Everyone wants to age in good health: mentally and physically fit. Statistics show that our life expectancy is increasing. The older we become, the greater the risk of developing dementia. “Reducing this risk in as many people as possible is the goal of the programme for dementia prevention” says Luxembourgish Minister of Health Lydia Mutsch on the national dementia prevention programme.

In 2017, major scientific research was published about the possible ways to prevent dementia. The results have given to the programme a tremendous boost: it is possible to selectively influence and reduce the risk factors for dementia.

**Dementia prevention programme: preventing or delaying dementia**

Don’t we all wonder once in a while if our forgetfulness is going beyond an entirely normal, occasional lack of concentration? Why are we having trouble following a conversation among several people? Is it normal? Or is it a warning sign of minor cognitive impairment, which might one day turn into dementia?

For people with mild cognitive impairment (MCI), there is reason to hope: an international expert committee published an assessment of the current state of play on dementia. It is possible to prevent or at least to postpone dementia. Risk factors including overweight, high blood pressure, depression, hearing loss or poorly balanced diabetes, as well as smoking, social isolation or lack of exercise have been identified.

People with a potential for a slight decrease brain performance and with a vulnerability to elevated risk factors can be referred by their treating doctor to the dementia prevention programme. They will be carefully assessed via specific exams, i.e. memory, attention and specific language tests. Neuropsychologists will create a personal cognitive profile.

These risk factors are then analysed in order to propose concrete measures: for people with a lack of physical activity, the solution is perhaps to register to a fitness centre. People who need to lose weight could maybe take cooking classes to adopt a healthy diet. Such joint activity can also help to prevent social isolation. Thus, the dementia prevention programme offers many opportunities for a better management of dementia risk factors. The intensive collaboration with the treating doctor is also an important part of the programme.

The programme experts are not only in contact with the treating doctors, but also with the partnering service providers. As Lydia Mutsch points out: “With the dementia prevention programme, we can now offer scientifically recognised actions to prevent dementia in people at risk. Every dementia case prevented through the programme is a wonderful success!”
Dementia in Europe

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POLICY WATCH


Ireland has waited more than 10 years to ratify and is the last of the 27 European Union Member States to ratify this international human rights treaty the UNCRPD

On 8 March the Irish Dáil (House of Parliament) passed a resolution enabling Ireland to finally ratify the UNCRPD. Ireland signed the UNCRPD in March 2007 and has waited more than 10 years to ratify and is the last of the 27 European Union Member States to ratify this international human rights treaty. To date the UNCRPD is the only human rights treaty ratified by the European Union (EU) as a whole.

Dementia as a disability

The UNCRPD does not create any new human rights. Instead, it states that all existing human rights apply equally to people with disabilities. States must take all necessary actions to ensure that people with disabilities are able to enjoy and exercise the full range of human rights.

There is a shift in tone in the way dementia is perceived, including the voice of the person with dementia: referring to “dementia as a disability” reframes dementia so that it is no longer seen as an inevitable part of old age. People with dementia have the right to services irrespective of age and “dementia as disability” would include people with younger onset dementia.

The human rights model

People make sense of disability in different ways, sometimes described as the models of disability. In 2017 Alzheimer Europe published a report “Dementia as a disability? Implications for ethics, policy and practice”. This report looked at several models of disability including the human rights model of disability for people with dementia. Although dementia is more now seen as a social disability rather than a medical disability, the human rights model works with the social model and recognises the person as an equal citizen and has his/her rights upheld and experiences full inclusion and equality. This can have a considerable impact on the lives of people with dementia.

A key aim of this approach is to ensure that people with dementia have the same rights as other citizens to contribute to society and that they enjoy the same benefits. This can be achieved through rules regulations and laws as well as carefully planned and meaningful involvement of people with dementia in society.

Using the UNCRPD

For instance, the UNCRPD could help to improve health outcomes, such as reducing the use of restraints and anti-psychotic medicines. The use of the UNCRPD as a tool for social change could be particularly useful in combating the stigma associated with dementia. The greatest single obstacle to the continued participation of persons with dementia in society arises from the stigma and fear of dementia amongst the general population and under-estimation of their capacity by politicians, professionals and researchers.

UNCRPD articles that are relevant to the lives of people with dementia

- Article 9: Accessibility
- Article 12: Equal recognition before the law/legal capacity
- Article 13: Access to justice
- Article 14: Liberty
- Article 15: Freedom from cruel, inhuman or degrading treatment

Helen Rochford-Brennan

Member of the Irish Dementia Working Group and Chair of the European Working Group of People with Dementia (EWGPWD), Helen Rochford-Brennan is delighted that the UNCRPD has been ratified.

“This convention can keep the will and preference of people with dementia at the centre of all decisions. There are specific articles in relation to people with dementia: article 12 deals with rights to equal treatment before the law; article 13 deals with having access to justice on an equal basis with others; article 19 deals with being included in your community, and article 27 is about no discrimination in employment. This is all about personhood. The Convention ensures that we can participate in society on an equal basis with others and I am delighted to see that it has finally been ratified.”

Helen Rochford-Brennan
Involving people with dementia

All parties who have ratified the UNCRPD are subject to evaluation by the UN committee. One of the recommendations from the concluding observations on the initial report of the European Union in 2015 was that the committee strongly encouraged the EU to involve civil society organisations, in particular organisations of persons with disabilities, in the preparation of its periodic reports.

People with dementia can be involved in the evaluation process and to look at the experiences of people affected by dementia in realising their rights under the UNCRPD and there are opportunities to highlight whether national provisions apply equally to people with dementia.

A course of action to achieve these aims is proposed for use by national Alzheimer’s Associations in partnership with people with dementia, their carers and other stakeholders. Actions can include:

- Engaging with the United Nations Committee on the Rights of Persons with Disabilities, including through its policy making processes,
- Encouraging and supporting national and regional Alzheimer’s organisations to participate in the examinations by the United Nations Committee on the Rights of Persons with Disabilities on their own country.

For example, Alzheimer’s Society UK Ambassador Keith Oliver (a person with dementia) recently participated in the examinations by the United Nations Committee on the Rights of Persons with Disabilities and was there to fly the flag on behalf of everyone in the UK affected by dementia. Putting rights at the heart of dementia policy and campaign work is a key priority for people with dementia. The UNCRPD investigation into the UK was an excellent opportunity to do this and was a significant opportunity to raise awareness of the rights of people with dementia and the need for action.

Otsuka: Proud to take the road less travelled

Today, more than ever, addressing unmet medical needs for people living with long term illness must go far beyond the conventional.

In central nervous system (CNS) disorders, there is still a lot that isn’t understood, and developing new treatments is a challenge. As a pioneer with a venture company spirit, we work with global partners to develop innovative new options in under-served areas such as Alzheimer’s disease.

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

*under development and not available yet

All Otsuka stories start by taking the road less travelled. For information about Otsuka Europe please contact +44(0)203 747 5000 or email: med.affairs@otsuka-europe.com www.otsuka-europe.com

Please always consult your treating physician regarding prescription medications for your condition
“Today marks a key moment, not only for people living with a disability, but also for their families, friends and support networks and for Irish society generally. Today we have seen all parties come together to demonstrate a shared commitment to the protection of the rights of persons with disabilities by approving the terms of the Convention,” said the Minister.

“Ratification of the Convention was a key commitment in the Programme for Government and has been one of the highest of priorities for me since becoming Minister. I am very pleased to now be able to deliver on that commitment.

“Becoming parties to the Convention provides a focus and structure to our journey, reaffirms our aspiration to improve the lives of persons with disabilities in Ireland and holds us to account in our commitments.

“It rebalances the right of people with disabilities to make decisions for them, rather than have decisions made for them. With ratification soon to be in place, I can now focus on using the Convention to better equip and resource people with disabilities to improve their quality of life.”

The Alzheimer Society of Ireland

“The Alzheimer Society of Ireland is delighted that a motion has been passed to finally ratify the UN Convention on the Rights of Persons with Disabilities (UNCRPD). We view this Convention as an important blueprint for improving the rights of persons with disabilities, including dementia. It is vitally important that people with dementia are empowered to participate in society on an equal basis with others.

“The UNCRPD will require Ireland to take extra measures to create an enabling environment and to remove the barriers to people with all disabilities in accessing their rights. This international agreement does not create new rights, but instead requires states to ensure, protect and promote the rights of people with dementia.

“This has been a long and hard road to finally ratify the Convention. As many people will be aware, Ireland signed the UNCRPD in March 2007 and we are now the final country in the European Union to ratify the Convention. We also acknowledge that while the Dáil motion moves ratification one step closer, there are legislative amendments that will be needed before Ireland will actually be in compliance with the Convention.”

The ultimate goal of the UNCRPD is to set out the rights of people with disabilities, and to provide a path to achieving those rights. By becoming a party to the UNCRPD, a State affirms these rights. It also commits to working towards achieving these rights within its laws, policies, and culture. The UNCRPD is an important piece of legislation which is relevant to help people with dementia enjoy human rights and quality under the law. The UNCRPD is also an important tool which dementia advocates, Alzheimer Associations and other organisations can use to advocate for change.

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The profile section contains information about Finian McGrath's role and contact details.

Image: Minister of State with Responsibilities for Disability Issues, Finian McGrath TD
Françoise Grossetête, MEP, discusses the future of the European Commission’s Health Programme and how dementia could be best addressed at European level

Françoise Grossetête, Chairperson of Alzheimer Europe’s European Alzheimer’s Alliance, speaks out on mid-term review of the Health Programme in the European Parliament

The European Commission is currently outlining their plans for the next budget [multiannual financial framework (MFF)] 2021–2027. One of the suggestions could be to include “food safety, human, plant and animal health” in a broader category related to the single market. What is your opinion on this and are you concerned about the possible disappearance of the Health programme in the next seven-year EU budget?

Of course, this of great concern to me. I had the opportunity to express myself publicly about that during a recent exchange on the mid-term review of the Health Programme in the Committee for the Environment, Public Health and Food Safety. (ENVI) Health is a concrete issue for all our fellow citizens. They care about their health much more than they do about the single market! Therefore, diluting the Health Programme within a broader budgetary line dedicated to the single market would make absolutely no sense to me. We would lose visibility and clarity on this very important and well-recognised programme. Even more so if human health is being mixed with policies on “food safety, plant and animal health”. Of course, these themes are all linked to human health, but they are not as important! It is all about the priorities we want to set for the years to come. We have asked the Parliament’s President to send a letter to Mr. Junker to make our preferences clear and I will remain vigilant.

Looking at the current Health programme, what do you think have been its main achievements so far?

There have been many, and it would not do justice to the Health Programme to mention just a few. It is a difficult exercise. However, I think it is important to be very concrete, so I will try to take two examples, which reflect well the usefulness of the Programme. The first one is the help provided by the Health Programme in setting up the European Reference Networks foreseen by the Directive on Cross-Border Healthcare. Those networks will allow to better tackle rare diseases through European level cooperation, knowledge sharing and pooling of expertise. A number have already been labelled by the Commission and are now being developed. They are a good example of what we can do better when work together rather than in isolation. Similarly, the Health Programme has been instrumental in supporting joint work on Health Technology Assessments, which has allowed the Commission to recently come up with a legislative proposal to harmonise those, with the aim of improving timely patient access to new therapies.

How do you think that issues like dementia should be addressed at European level and what could be future priorities of European health action for dementia in the future Health Programme?

First, we very well know that there is a lot of room for improvement in the way dementia is being addressed by our health systems. The focus I believe should be on research and prevention, but also diagnosis and support to patients and carers. Given there is unfortunately so much room for progress, the panel of possible EU health action for dementia is rather broad. This is why I think fighting dementia should be an overarching aim of the Programme and not only a part of the Annual Work Programmes. Moreover, particular support should be granted to initiatives aiming at prevention and early diagnosis of the diseases associated with dementia, as I think we have to better address those diseases before they appear and degenerate.

“The focus I believe should be on research and prevention, but also diagnosis and support to patients and carers.”

Profile
Françoise Grossetête, MEP (EPP, France) is one of the Alliance’s founding members and she has been its chairperson since 2007. She sits on the Environment, Public Health and Food Safety Committee and is a substitute on the Industry, Research and Energy Committee.

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Deirdre Clune, MEP, submits European Parliament written question to the Commissioner on the Expert Group on Dementia

Deirdre Clune, member of the European Alzheimer’s Alliance, asks why the Expert Group on Dementia has been disbanded

Deirdre Clune, MEP, member of the European Alzheimer’s Alliance has submitted a Written Question to the Commissioner to address the question of why the Expert Group on Dementia has been disbanded. This happened at the same time as the disbandment of the expert groups on cancer, rare diseases and mental health. Instead of these specific disease groups the Commission has created a new group called the Steering Group on Prevention and Promotion.

Alzheimer Europe is disappointed to see the Expert Group on Dementia disbanded. The group provided an ideal platform for government representatives to share good practices on the dementia policies and national dementia strategies which different countries are and were in the process of developing or implementing. The group was also helpful in bringing together Commission representatives from DG Research and from DG Social Affairs to explore how to better coordinate work across different Commission services. In addition, the group provided an important link with the 2nd European Joint Action on Dementia which is coordinated by the Scottish Government and supported by the health programme and which looks into timely diagnosis and post-diagnostic support, care coordination and crisis management, residential care and dementia-friendly communities. The group was also able to link up with the important work done by the World Health Organization and by OECD in the field of dementia and explore synergies between EU and more global initiatives. Finally, Alzheimer Europe had consultative status with the group and could update government representatives on its initiatives and projects. At a time where a growing number of EU Member States recognise the importance of dementia as a public health priority this Commission decision to disband the expert group unfortunately took away a very important mechanism for these countries to exchange on policy initiatives and learn from one another.

European Parliament

Question for written answer to the Commission

Rule 130

Subject: Dismantling of the Commission Expert Group on Dementia

Dementia is a major public health issue. By 2060, 28% of the population will be aged over 65 and 12% aged over 80. In 2015, dementia affected some 10.5 million citizens aged between 30 and 95+ years of age in Europe. This number is estimated to increase to 13.42 million people by 2030. Dementia accounts for 11.9% of the years lived with disability due to a non-communicable disease. There is still no cure for dementia.

1. With regard to these figures and the growing public health threat of dementia, why has the Commission dismantled the Government Expert Group on Dementia, which included the participation of Member States and civil society and enabled them to go back to their respective national and European authorities to share expertise and good practice?

2. How does the Commission now intend to encourage Member States to share expertise and good practice and to adopt national strategies regarding Alzheimer’s?

3. How is the Commission now taking stock of the various recommendations that EU Presidencies have made on dementia and the findings of research programmes such as the Joint Action on Alzheimer Cooperation Valuation in Europe (ALCOVE) and the 2nd EU Joint Action on Dementia?
What are the repercussions for dementia of the United Kingdom leaving the European Union

Colin Capper from the Alzheimer’s Society UK talks about the implications of Brexit for people affected by dementia

From the perspective of many in Europe (and a surprising number in the UK), Brexit has been decided and we are moving on. However in April 2018, nearly two years since the referendum, Europe and the UK still don’t have a clear picture of their respective positions in relation to, not least many areas of policy, but also research and development and for patients.

The implications of Brexit could be wide ranging and are unknown but what is of concern is uncertainty. Those working on the front line of research: researchers, PhD students, clinicians and others are likely to be affected and there is growing concern about the impact Brexit could have on people affected by dementia in the UK and across Europe, both immediately and in the longer term. The sense from many working in the dementia research field is that we are at a crucial tipping point which we cannot afford to fall back from.

Funding and collaboration

Leaving the EU could mean the UK is designated the status of ‘third country’ and as such will lose direct access to many EU research funding schemes. We are all agreed that EU funding is critical to the strength of the UK research base and although the UK government has agreed to underwrite European Structural Investment Funds and Horizon 2020 this is hugely worrying for the longer term future of UK based research.

Research is, by its nature is international and collaborative, bringing benefits to all parties. A Royal Society report demonstrates that 80% of the UK’s international publications included co-authors from the EU. If investment in UK dementia research shrinks due to Brexit, it is inevitable that collaboration between the UK and EU countries will weaken, ultimately reducing research capacity and capability across the continent.

The UK is currently involved in a large number of innovative multi-centre clinical trials taking place across Europe. Without continued European funding and collaboration these opportunities for people living with dementia in the UK to take part in cutting edge studies are likely to reduce or dry up altogether. Opportunities such as these are a real source of hope and motivation for many living with the condition today. Additionally, removing UK from the equation could make recruitment to both large non-commercial and pharmaceutical led studies more difficult which unfortunately could affect those across Europe as well.

“I joined the research network when I lost my mother to be part of a wider movement to defeat dementia. If we are isolated, we all stand to lose a lot.”

Alzheimer’s Society volunteer

Workforce

It doesn’t come as a surprise to many in the world of research that 26% of UK academic staff are EU nationals. For example at University College London home to the UK Dementia Research Institute partly funded by Alzheimer’s Society, 21% of the workforce are EU nationals. The question of freedom of movement is a key red flag for all those working in research. Anecdotal reports suggest due to the uncertainty around recruitment as well as funding, there has been active discouragement in applying to EU funding schemes and hesitation in some recruitment applications.

“It took six months longer than expected to recruit to key roles, this has had an impact on the rest of the project.”

Alzheimer’s Society Grant Holder

The UK is a hotbed of innovative and leading dementia research but it wouldn’t be what it is today without its EU workforce. It provides opportunities for, and attracts budding researchers from an extensive European network who are starting out in research and who will be the future leaders in dementia research.

In the short term, research institutions may well cope with these changes but ultimately the long term impact could lead to a reduction
in the number of research leaders in the field and slow down the great progress being made today in dementia research. Improvements to care and treatments for people living with dementia can’t come soon enough and this is just another bump in the road.

Regulations and the European Medicines Agency (EMA)

The EMA, currently based in London but due to relocate to Amsterdam by March 2019 (when the UK officially leaves the EU) is a vital component in the drug regulation pathway and therefore plays a key role in determining access for UK patients to new and cutting edge treatments. With Brexit, nothing is certain and this includes the future relationship of the EMA and the UK. It is crucial to all patients that the UK secures a deal on how it will either remain part of the EMA or at the least align with it to ensure timely access of new treatments for those across the UK.

With no new treatments available to people living with dementia for 15 years now, the smooth transfer from late stage clinical trials and use in society is vital. It would be a shameful and likely costly situation if patients are forced to wait longer for treatments to be approved.

Care and support

At the last count, the UK growth forecast had been revised down to 0.4% for 2018, alongside budget pressures which are already impacting both health and social care services, putting the National Health Service (NHS) under a huge strain.

“The forecast negative impact on the UK economy will have a direct impact on people affected by dementia and their families who already meet 2/3 of the £26bn cost of dementia care”. Dementia UK report 2014, Alzheimer’s Society.

Although awareness and education both in and out of the health sector is rising, care services are struggling to support those at the later stages of dementia, thereby placing an ever growing burden on family and relatives.

The future: a response from the UK and Europe

Continuing engagement between the UK and Europe is a win-win situation. However, it should be made clear that a lack of commitment to this relationship in the coming years will be a lose-lose situation for all those involved.

The UK must take the lead for people with dementia and is already taking action through the Prime Minister’s Challenge on dementia alongside the Association of Medical Research Charities’ (AMRC) with a joint response to Brexit that has highlighted key areas of concern including:

- patient access to trials,
- medicines and treatment,
- alignment with EMA,
- clarity on funding.

An international campaign

The Brexit Health Alliance which brings together NHS, medical research, patients and public health organisations is already playing a key role ensuring the future relationship between the UK and Europe is nurtured and maintained from both sides.

The real risk we run as an alliance is not striking the right deal that will maintain the mutually beneficial partnership we currently have in place. This is a key moment for all those involved in the alliance to consider the implications of all those living with dementia today and in the future and ensure that at this crucial tipping point we don’t lose momentum.

The UK has made a decision on its future and as such must follow its chosen path. We call on Alzheimer Europe members to raise this issues to their respective governments on the importance of maintaining this vital relationship especially putting the interest of patients first. The UK has not left the European Union yet, how we leave and the nature of continuing cooperation and collaboration beyond March 2019 will have implications for people affected by dementia across Europe.

If the UK and European nations raise this as a key item as an international campaign on the agenda we may be able to reduce the negative impact that will be felt by all those in the field but particularly the disproportionate impact that could fall with people living with dementia.

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Brexit: the implications for researchers

Researchers are not reassured but value collaboration

- UK’s share of Horizon 2020 funding fell by 20.5% between 2015 and 2017 (Nicholson 2017)
- “I have given up on Horizon 2020" (Researcher)
- “Collaborative work is being done, but UK researchers are no longer being included in some EU bids” (Research Network Volunteer)
- “My colleagues ask me why I’m bothering when Brexit will kill the funding” (Researcher)
- The benefits of collaboration are worth the effort now needed. This isn’t UK researchers getting in before we get out. (JPND Grant Manager).
POLICY WATCH

The new General Data Protection Regulation comes into force

Nigel Hughes, Scientific Director, Janssen Pharma R&D explains the implications of this new regulation for the Alzheimer’s community

What is real world data, and why is it important?

If you or someone close to you is living with Alzheimer’s disease, or another dementia type, clearly, we all want to see potential treatments to reduce the impact, burden and eventual consequences.

Understanding how the diseases progress, their natural history, and who are at risk of developing dementia, how different people progress differently, and insights into potential ways to manage, treat and someday cure them is based on research. This research can be both studies, such as clinical trials and laboratory-based work on the biology, or insights generated from using data from the clinic or generated by people living with dementia (PLWD), or their carers.

This data, the information on specific aspects of a PLWD’s life is called real world data, as it is reflective of what is happening in a real-world setting, the clinic or hospital, the person’s home or in their community, and is not data generated in an artificial setting of a research study or drug trial.

Today we are seeing a revolution in how we are understanding ill health, a person’s experience with it, and the impact on their quality and quantity of life, due to the sheer volume of data being generated by each of us, our carers, healthcare providers and allied individuals and services, as well as more advanced techniques in examining our DNA and biological functions. Of course, such health data is personal to the individual, and as such personal data is very sensitive, requiring perhaps special treatment compared to other data in society.

Many suggest we are now in a situation where we are drowning in data, but thirsting for knowledge, as we face the challenge of how to organise, prioritise and analyse this data to answer critical questions. For instance, why do some people live to a very old age, perhaps over 90 to 100 years old, but do not progress to symptomatic dementia, even with evidence of changes in their brains, such as amyloid positivity, while others progress to fully fledged dementia at a much younger age. Why do we see no difference in progression to mild cognitive impairment or dementia in identical twins, but in some other identical twins we see a difference in progression between those pairs?

Furthermore, what can we do to try to prevent, or at least slow progression to dementia, or if too late, stop progression, or even reverse it? A number of real world data projects have been investigating this in recent years, such as the Alzheimer’s arm of the European Medical Information Framework (EMIF, and EMIF-AD), ROADMAP, and also others such as EPAD, which is working to expand the opportunity for PLWD to being involved in research and drug studies.

None of this is, I am sure, very new to many of you reading this, but the conditions under which we protect, interact, organise, manage and use all of this data will change on 25 May 2018.

If we are to make progress against dementia, real world data is really important, and data sharing, under the restrictions of the GDPR, needs to be supported”

Sources of patient real world data
“Today we are seeing a revolution in how we are understanding ill health, a person’s experience with it, and the impact on their quality and quantity of life, due to the sheer volume of data being generated by each of us.”

Up until this year, all data, whether in healthcare, or other aspects of society, was protected by the Data Protection Directive (95/46/EC), adopted in 1995. Unfortunately, technology and the use of all types of data is progressing so quickly that this directive is now already very outdated. It also was an EU directive, so this meant all Member States could interpret this nationally, meaning a fragmented approach across Europe, and for many it left many areas difficult to interpret, and without sufficient enforceability.

After considerable negotiation, the EU Parliament agreed the General Data Protection Regulation (GDPR, EU 2016/679) in 2016, with a transition period of two years to support its implementation. On 25 May 2018 it will come into force, replacing the prior EU directive.

What does this mean for PLWD and their carers, and for research into dementia?

The GDPR is fundamentally an update to the prior directive and many things do not necessarily change. However, a number of aspects of data privacy and security have been clarified and improved, with increased powers for EU citizens, as well as responsibilities for organisations generating, storing and/or using personal data. The following is a guide to some of the major changes with the GDPR, but it is not exhaustive. Some aspects are also potentially less or enforced differently in the research setting:

- **Consent**: this has been significantly strengthened. Anyone asked to share their personal health data needs to be asked in plain, understandable language, and their understanding of the process, and the implications, needs to be able to be documented. It also must be easy to be able to withdraw consent at any time as well, though there may be some restrictions on the need for consent or the ability to withdraw consent for example in research. This must be agreed by relevant authorities in organisations and EU countries. Overall, it must be clear to any EU citizen what their data is being used for (lawfulness, fairness and transparency).

- **Purpose limitation**: any data collected needs to be used for a specific purpose, and for no other purpose beyond that without further consent. For the purposes of research, such in Alzheimer’s disease and dementia, it is proposed that data can be re-used, without breaking this rule.

- **Data minimisation**: any personal data collected needs to be relevant and necessary only for the purposes consented for. For instance, in a study with PLWD, data collection can only be on the information that meets the study goals, and not unconnected areas not serving the purposes of that research and again needs to be consented for.

- **Accuracy and right to access**: any personal data collected needs to be accurate, and now an EU citizen has the right to ask for copies of data stored, and the ability to request mistakes or incorrect data to be corrected. This could be as simple as a mistaken address, or more complicated, such as an error in a medical record. All personal data must be stored to protect confidentiality and to protect its integrity (accuracy and consistency).

- **Portability**: this allows for personal data to be transferred between organisations, or to the EU citizen, on request, which is very important in providing greater control to the individual. Personal data is already routinely shared for healthcare reasons under professional secrecy to meet the needs of healthcare, such as different specialists managing the care of PLWD.

- **Right to be forgotten**: now any EU citizen could request the removal of certain data. This could be due to the right to withdraw consent, or due to the end of a study, or if in the public domain to protect your rights or privacy. Storage of data is also limited by the purpose limitation, so it cannot be stored indefinitely, unless with prior agreement and consent, or due to another legal requirement.

- **Accountability**: there are many more responsibilities for anyone or any organisation who are responsible for personal data (controllers) and who may use it (processors), requiring proof of compliance with the GDPR. If there is a breach of this accountability, there are clear responsibilities to inform EU citizens of what went wrong.

- **Penalties**: for anyone getting this wrong, and not complying to protect an EU citizen’s personal data there are now considerable consequences, including to their public reputation, as well as financially.

For many, the GDPR is a significant step forward in international standards on personal data protection, and it likely will set not just a European, but also a global standard. In saying this, there are still many challenges in interpreting the GDPR and implementing it and it is likely that many organisations will not be ready on 25 May (technically in breach). A recent article in The Lancet spoke about the concerns some have in the research community about the insufficient guidance to date.

For Alzheimer’s and dementia research, there is no evidence that GDPR will make this more difficult, though it has strengthened the rights of PLWD and their carers significantly.

If we are to make progress against dementia, real world data is really important, and data sharing, under the restrictions of the GDPR, needs to be supported.
At Roche, we work with a purpose.

We discover and develop innovative medicines and diagnostic tests to help people live better, longer lives.
Actress Carey Mulligan, speaks about her work as an Alzheimer’s Society UK, global dementia friends ambassador

Carey Mulligan shares her own personal experiences of dementia and her hopes for the future by being part of the global dementia movement

I have been so proud to support Alzheimer’s Society for many years now – both at home and abroad – and be part of the vision of creating a world without dementia. In all of those years, it has never felt like such an exciting time to be part of this growing, and truly now global, dementia movement.

Now it feels like we’re on the cusp of change. Real change. And together we can make the difference that people living with dementia want to see, deserve to see and most importantly, have the right to see.

I remember being in a tube station in London once and I saw a lady really struggling to get through the barriers before the days when you could use a credit card. She was trying to use her credit card to get through but she needed a paper ticket.

People were standing behind her getting really annoyed but nobody was really doing anything and I wanted to intervene. I wanted to help her, and I did eventually, but I had that moment where I thought “Oh, I don’t want to embarrass myself,” and I really didn’t want to embarrass her. I ended up plucking up the courage and I put my ticket through to show her, she then put hers through and she was fine and went on with her day.

I had similar experiences in a dementia care home. My grandmother, Nans, who passed away last year from dementia, was in a home and I first went there when I was about 21 years old. I remember being so nervous to talk to other clients who lived in the home. I didn’t know how they would react and I didn’t know how capable at that point they were of verbal communication so I just clammed up. I would hesitate before speaking to people because I didn’t want to look foolish or worse; upset anyone! I quickly learnt that actually most of the time they wanted to talk. They wanted to tell stories or chit chat about their families and it just took that moment of me getting over myself and my concern about ‘getting it wrong’ to be able to have really lovely conversations that we both appreciated.

Dementia Action Week in June was a really crucial time to get the word out and to galvanise people to take action, however big or small, easy or challenging, and get everyone involved to improve the lives of people with dementia.

And there are simple things we can all do in our everyday lives to be more dementia friendly and remove stigma. But I think part of our dementia movement and turning awareness into action is acknowledging that we might sometimes need to step out of our comfort zone in order to do it. We might need to take that risk, to do the slightly difficult thing. But the reward of a more dementia friendly society will be more than worth it.

Profile
Carey Mulligan became the ambassador of the Alzheimer’s Society in 2012, with the goal of raising awareness and research funding for Alzheimer’s and dementia. Her grandmother lived with Alzheimer’s disease. She helped host and participated in the 2012 Alzheimer’s Society Memory Walk and was one of the sponsored Alzheimer’s Society runners in the 2013 Nike Run to the Beat half-marathon in London.

“ I think part of our dementia movement and turning awareness into action is acknowledging that we might sometimes need to step out of our comfort zone in order to do it”
Lilly and Alzheimer’s Disease

For nearly 30 years, Lilly has been committed to Alzheimer’s disease research and development. During this time we’ve made significant scientific advances and we’re not slowing down. In fact, our commitment is stronger than ever. Through perseverance and discovery, our goal is to make life better for those affected by Alzheimer’s disease around the world.
World Rocks Against Dementia (WRAD) campaign reaches out to wider community

Events around the world use music for raising awareness and supporting those with dementia and their families.

Rock Against Dementia began in the USA when Wayne Mesker and Michael Rossato-Bennett of the Alive Inside Foundation were promoting musical events with the aim of fundraising for headphones to bring free music to residents of care homes. Music has been shown to be of huge benefit to those living with dementia.

From that humble beginning a few years ago Wayne Mesker was contacted by Norms McNamara, a global advocate for dementia and founder of the global-Purple Angel dementia awareness campaign. He himself lives with a diagnosis of Lewy body dementia and is very active in working to help reduce stigma of dementia. Norms McNamara asked if he could change the Alive Inside promotion to Worlds Rocks Against Dementia, or WRAD as its now known, because the Purple Angel Campaign is known all around the world and it could turn a single country event into a global event. Thankfully, Wayne agreed and the rest, as they say, is history!

WRAD, Nigeria

World Rocks Against Dementia (WRAD) has taken place for the last three years. In 2017 there were 76 events in 12 countries and in March 2018 85 events took place in 20 countries. Venues ranged from in care homes and others were huge fundraising parties. Ticketed events and raffles took place along with an on-line event staged by Dementia Alliance International (ADI). Funds were raised for some of the big dementia charities but also for local Memory Cafes and other smaller voluntary efforts raising awareness of dementia. In 2018 events were also held in memory of Glen Campbell, David Cassidy and Malcolm Young from AC/DC who all passed away from dementia in 2017.

Any kind of music counts, rock, country, western, classical or traditional and any funds raised can be used for a dementia project of choice.

Music for people with dementia

Music activates certain regions in the brain which are involved in movement, planning, attention, learning and memory. Music can release dopamine in the brain which lessens anxiety and improves mood. Music gives pleasure and brings back lost memories. It helps to boost the immune system and creates a feeling of wellbeing with good feelings which boost the immune system. It also allows people to recall personal memories and can relieve pain. When you enjoy your favourite music it can give all these benefits and more besides. Improved concentration levels allow people with dementia to “come alive inside”, speaking, singing along and smiling as they may not have done for a long time.

Purple Angel is a global movement comprised solely of people who volunteer their time to raise awareness in shops and businesses, run memory cafes, befriending services, day care centres, care advice, training in hospitals, ponies for health, conferences and many other actions throughout the world.

European countries which joined in this year were: the UK, Ireland, Cyprus, Spain, Gibraltar, Hungary, Finland and. Denmark.

It is hoped that the 2019 event will be even bigger and that many more large charities will see the benefits of joining in too!

Purple Angel Movement
Norms McNamara or Jane Moore
www.purpleangel-global.com

Alive Inside Foundation
Wayne Mesker and Michael Rossato-Bennett
www.aliveinside.org/WRAD
www.youtube.com/watch?v=Hlm0Qd4mP-I
www.facebook.com/WorldGoneRAD
Croatia and Slovenia successfully complete EU Demenca aCROsSLO project

Cross-border co-operation between Croatia and Slovenia improves the quality of life of persons with dementia

The improvement of the quality of life of persons with dementia in the cross-border area of Croatia and Slovenia was the main objective of the 18 month long European Interreg project Demenca aCROsSLO, which ended in March 2018. Thanks to this project, among other things, 330 dementia specialist nurses were educated in Croatia and Slovenia and recommendations for designing dementia departments in retirement homes, workbooks for family caregivers and an educational video has been published. Among the key outcomes of this project are the recognition of the need for the development of dementia-friendly communities as well as the continuous alignment of care for people with dementia between Croatia and Slovenia.

The project partners were retirement homes from the Croatian town Umag and neighbouring Slovenian cities of Izola and Koper as well as the City of Umag, Alzheimer Croatia and the National Institute for Public Health of Slovenia.

**Education**

Project Demenca aCROsSLO started with a study of the state and needs of retirement homes. From this basis an extensive training programme was created, whose development was led by Alzheimer Croatia. The training was divided into three parts:

- General approach to dementia and recognition of first symptoms of dementia;
- Behavioural and psychological symptoms of dementia and ways of controlling them with non-pharmacological approaches;
- Nursing and communication with people with dementia and their family caregivers and managing of the dementia departments.

The programme was successfully completed by the staff of partner homes as well as many other professional carers and social workers in the region. The educators were leading Croatian and Slovenian scientists, university professors and practitioners who put a special emphasis on psychosocial approach to people with dementia. The evaluated training results showed great success.

**Home care services**

Analysis have shown that Croatian home help services for people with dementia are not as developed as in Slovenia, and that there is a lack of data in both countries that helps to better track these services. This is why the transfer of knowledge and experience from the retirement homes with such services in the Slovenian city of Koper and the Croatian city of Umag has been agreed. New tracking software for smartphones and tablets has been developed which now facilitates work for carers and provides more time to work with people with dementia. There are more people employed in Umag and the results show that the services in this region are now even more uniform. For easier recognition of the dementia symptoms for home help service providers, Alzheimer Croatia with other project partners has also developed guidelines for the identification of signs of dementia and further procedures.

**Caregivers workbook**

The National Institute for Public Health of Slovenia led the development of the “Workbook for Family Carers of People with Dementia”. Its main parts contain many cognitive exercises, space for writing childhood memories, colourful images reminiscent of their smells and demanding people with dementia to evoke their names, as well as many traditional easy singing songs. This booklet is already a hit on Facebook and has already
been downloaded hundreds of times. It is a disadvantage that the budget constraint of this project did not allow for printing of this workbook in a larger edition, as most older people are not comfortable reading it on a computer screen.

Design recommendations

Recommendations for department design for people with dementia in retirement homes, which were conceived as a small booklet, eventually became large format textbook with over 200 pages, and is the first one in Croatia and Slovenia. Development of this book was led by the office for social activities of the City of Umag, and supported by a multidisciplinary team of dementia consultants, architects, designers, family doctors and social workers. Recommendations are based on the latest scientific findings in this area and the best practice in the world. The role of Alzheimer Croatia in this part of the project was to develop design principles and to write recommendations for indoor environments and signposting to assist with editing and to create the layout of the book.

The content of these well illustrated recommendations covers all relevant topics, comparing the existing regulations relating to dementia departments in retiring and nursing homes, present principles of universal design suitable for people with dementia, approaches to urban and architectural planning as well as design of indoor environments and open spaces and parks that surround retirement homes. A large appendix of this book consists of many examples of architectural layouts which point to ways of approaching such planning. This long-awaited book will be not only a guide for architects but also for many owners of small homes for the elderly who mostly do their own adaptations themselves. The Croatian and Slovenian ministries of social affairs are already praising this work and it is expected that they will accept these recommendations as the starting point for adopting new regulations on the planning or renovations of appropriate dementia departments in retirement homes.

Fighting the stigma

During this project, all of the partners were very committed to communicating with the public aiming at destigmatisation of dementia. In addition to numerous media appearances, more than 40 events, meetings of people with dementia and their family caretakers and public lectures and Alzheimer’s cafes were held covering audiences of more than 1,600 people. All of them received a flyer How to live with dementia and saw a film – Dementia – the public health problem of today, whose creation was led by Alzheimer Croatia. Coordinator of communication activities was the National Institute for Public Health of Slovenia who also created a newsletter distributed to more than 3,000 addresses.

Dementia friends’ initiative and dementia friendly communities

Among the key outcomes of this project is the recognition for the need for the development of dementia-friendly communities and strengthening of the dementia friends’ initiative, which Alzheimer Croatia has been developing in the meantime. Up until now the cities of Zagreb (municipal of Croatia) and Umag have started the process of becoming dementia-friendly communities, and more Croatian cities are preparing themselves for the same process.

Need for joining the Global dementia Friends initiative recently was recognised also by Alzheimer Slovenia.

Further developments

Dissemination of the results so far has contributed to other retirement homes wanting to educate their staff using the same programmes and to update their dementia departments according to the new recommendations. In one cross border area in the North Adriatic region where the Dementia aCROsSLO project started, two working groups have been established consisting of professional carers and social workers who have begun their long term collaboration on further development of living conditions for people with dementia in the area and whose findings and results will be grounded for strengthening the future cooperation of the Croatian and Slovenian ministries of health and social affairs.

aCROsSLO

Leading project manager Mrs. Alenka Volk
Leading project partner: Retirement house Izola (Dom upokojcev Izola, Slovenia)

demenca.acrossslo@du-izola.si

Tomislav Huić, Training Group Leader of the EU project Demenca aCROsSLO, Vice president Alzheimer Croatia, Director of Dementia Friends Initiative Croatia

tomislav.huic@alzheimer.hr

DEMENTIA IN SOCIETY

Dementia in Europe 33

Video and print materials created during realization of the Demenca aCROsSLO project
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Janssen Pharmaceutica NV
Finland’s Memory Activists involved in development of palliative and end-of-life care

Memory Activists, the Finnish working group of people with memory diseases and their family members, emphasise that equal access to palliative treatment and end-of-life care throughout the country must be ensured.

Finland’s Memory Activists are participating in the discourse of palliative care, terminal care and euthanasia. In December 2017 they released a brief statement regarding the issue, which says that the faith in peaceful end-of-life care and death can alleviate the fear of death. The Memory Activists hope that their views will be taken into account in the development of palliative care, terminal care and possibly euthanasia in Finland.

In February 2016, the Ministry of Social Affairs and Health assigned an expert working group which was tasked to draft a recommendation for providing palliative care and end-of-life care. The working group released its report in December 2017.

The recommendation proposes qualification and quality criteria for different levels of the social welfare and health care service system. It calls for measures needed to develop the training and expertise of social welfare and health care professionals. At the moment the education of health care professionals on the basic and postgraduate level does not provide enough knowledge for palliative and terminal care.

The recommendation is based on a three-tier model for providing services at the basic, specialised and intensive level. This three-step model will serve as a basis for the regional planning of service chains.

Question of better education

The Alzheimer Society of Finland participated actively in the discussion on palliative care and end-of-life care by articulating the views of people with memory-related diseases and their families. In October 2017 the Alzheimer Society released a statement related to the report of the ministry’s working group. The Alzheimer Society of Finland underlined that it is crucial to listen to the opinion of people with memory-related disease and their family members when arranging palliative care and end-of-life care. The end-of-life care plan should be discussed openly and honestly with them.

“It is crucial that people with memory-related diseases can participate in the discussion and that they can make their voice heard. We work together with Memory Activists to raise the awareness of development of palliative care and end-of-life care in Finland”, says Eila Okkonen, the Executive Manager of Alzheimer Society of Finland.

The Alzheimer Society of Finland stresses that the rights of people with memory-related diseases must be respected at all phases of life. It participated in the project called Good Death to develop end-of-life care with a well-known Finnish hospice. The society has also published a guide book The Good End-of-life Care of Person with Memory-related Disease.

The Alzheimer Society of Finland emphasises that family members’ role is crucial. They must be able to take part in discussion and decisions made in care settings. Far too often they don’t get enough information or they don’t understand the information they’ve got. The regular discussion with the families should be a common practice.

The Alzheimer Society of Finland wants to point out that the need for further education in palliative care and end-of-life care is essential and that educated staff is key to the more peaceful final stages of life.

Honest discussion

In Finland there’s a lot of public discussion about euthanasia. A form of participation at national level, citizens’ initiative, offers people the possibility to have their initiative considered by the Parliament. This spring, the Parliament’s Committee of Social and Health Affairs Parliament considered an initiative that promotes the legalisation of euthanasia in Finland. It gathered 63,000 names.

In April 2018, the Parliament’s Committee proposed unanimously that the citizen’s initiative should be proposed that at this time steps towards legalisation of euthanasia should not be taken. However, based on

“Our experience is that the quality of palliative and terminal care varies a lot. We are sure that everybody wants to have palliative care and end-of-life care as close to your home as possible when the time comes”

Jouni Rasi
the expert hearings, it emphasised that end-of-life care should be improved. That aspect raised in the hearings of experts. The plenary session of Parliament makes the final decision in euthanasia initiative in the near future.

Last year the former chairman of the Memory Activists, Jouni Rasi, opened the discussion among the Memory Activists about euthanasia. He proposed that there should be a vote for members of Alzheimer Society of Finland. In further discussion of Memory Activists that was considered to be too challenging.

The Memory Activist talked about how well the equal access to good palliative care and end-of-life care comes true in different areas of Finland. They pointed out that people are in unequal position depending on where they live. Especially if you live on a small place it cannot be ensured how well professional care is available on the final stage of life. They discussed also if the care of people with memory-related diseases in the terminal phase is as good as it is with other diseases.

“Our experience is that the quality of palliative and terminal care varies a lot. We are sure that everybody wants to have palliative care and end-of-life care as close to your home as possible when the time comes”, says Jouni Rasi.

“I’ve got very positive feedback from our statement. It is considered very remarkable by people with memory-related diseases and their family members. We’ve expressed our opinion in good time”, he continues.

The advanced directive plays a key role

The advanced directive plays a key role in the care of people with memory-related disease. It is important that the opinion and one’s own wishes are defined in it. The written advanced directive should be kept up-to-date and it could be attached to Finnish database of patients.

The Alzheimer Society of Finland speaks about active advanced care.

“It is very important that you can express your opinion on the advanced directive and that you can update it easily if your opinion changes later”, Jouni Rasi emphasises.

The ability to communicate alters when the memory-related disease proceeds. People communicate in different ways and often the question is more about one’s will to understand.

“The Alzheimer Society of Finland wants to point out that it is necessary to discuss
palliative and end-of-life care already on the early stage of memory-related disease at peace”, Eila Okkonen says.

The Memory Activist discussed how the decision of terminal care is made and how well the voice of family members is heard in that situation. They emphasised that it is crucial that the terms and changes in care are communicated clearly so that everybody can understand them and you know what exactly is going on.

Eila Okkonen stressed that the decisions and changes in care must be well discussed and informed. The Alzheimer Society of Finland get sometimes feedback that the family members are not informed well enough about the changes in the care.

**It’s time to act**

At the moment there’s a fundamental social welfare and health care reform going on in Finland.

“The wide-range reform is one reason why we must act and speak out loudly now. It must be taken seriously that there is enough expertise available in the palliative care and end-of-life care in the new social and health care centres. In every county it has to be ensured that there are good hospices for terminally ill people as well”, says Jouni Rasi.

“I hope that we can talk about good death openly. Death faces us all eventually and good death should be of concern to all of us”, he continues.

**The statement of the Memory Activists**

Regarding the discussion about the palliative care, terminal care and euthanasia in Finland the Finnish national dementia working group, Memory Activists wanted to emphasise:

- The advanced directive should be respected in all care settings and kept up-to-date.
- Palliative care skills and procedures should be developed so that a patient can get excellent palliative care in all care settings.
- The diagnosis does not occur alone – memory-related diseases should be considered in the care plans of other diseases.
- The choices and principles regarding palliative care, terminal care and possibly even euthanasia should be equal in all parts of Finland and in different care settings.
- The end-of-life care plan should be discussed openly and honestly with both the patient and family members.
- The faith in peaceful death is key to good life.
A look Behind the headlines: A blood test to diagnose Alzheimer’s disease

Dr Philip Scheltens, Professor of Cognitive Neurology and Director of the Alzheimer Center at the VU University Medical Center in Amsterdam comments on a new study of a possible blood screening test which could improve diagnosis and drug trials for Alzheimer’s disease.

Research into Alzheimer’s disease is shifting from the later dementia stage towards the earlier stage in which people have either mild cognitive impairment, subjective complaints or no complaints at all. However, to detect Alzheimer pathology in vivo one needs either an invasive Lumber puncture (LP) to withdraw Cerebral Spinal Fluid (CSF) for analysis of the biomarkers Aβ, tau and p-tau, or one needs to undergo an amyloid PET scan which is costly and not widely available.

The research field has long been trying to find a biomarker that is more easily accessible and obtainable that could serve as a funnel biomarker, i.e. a marker to test who would need to undergo further CSF or PET testing. The hope has always been that a biomarker in blood would become available to facilitate this. Especially for testing new treatments, people with or without complaints and positive biomarkers are the population of choice at the moment, but the question is how do we identify these subjects.

What is the new blood test and does it hold promise for people with Alzheimer’s disease?

Now, in a study published online on 31th January in the journal “Nature”, a team of Japanese and Australian researchers reported a screening test that may help the field further. They have discovered a blood test can predict levels of amyloid-β deposition in the brain, by comparing results from the blood test with amyloid PET images and CSF values of amyloid in 373 participants ranging from healthy to mild cognitive impairments or Alzheimer’s disease (AD) from Japan and Australia.

The technique should be transformed into a test that can be done reliably in other laboratories and is far from clinical use. However, it requires sophisticated machinery and laboratories and is far from clinical use. However, the results are promising and important because they may open the route to finding more and better biomarkers in blood to be used on a population level, and ultimately for screening purposes (similar to those we already know for breast and cervical carcinoma). The researchers acknowledge that there are still several issues that need to be addressed before considering a more general widespread application, let alone clinical use. Validation studies in other cohorts, coupled with longitudinal cognitive data as well as other dementias are crucial.

The technique should be transformed into a test that can be done reliably in other laboratories with easier and standardised analytical methods, such as Enzyme-linked Immuno-sorbent Assay (ELISA’s). As said, tests like these may open the door to low threshold screening tests in large populations to find people at risk of developing AD when treatments have become available.

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

So yes, we can be excited, not only because of this specific study, but also because it may accelerate other studies in other groups working at blood tests and hopefully will accelerate drug development as well!

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

The technique is not straight forward and requires sophisticated machinery and laboratories and is far from clinical use. However, these results are promising and important because they may open the route to finding more and better biomarkers in blood to be used on a population level, and ultimately for screening purposes (similar to those we already know for breast and cervical carcinoma). The researchers acknowledge that there are still several issues that need to be addressed before considering a more general widespread application, let alone clinical use. Validation studies in other cohorts, coupled with longitudinal cognitive data as well as other dementias are crucial.
Our members are helping people with dementia and their carers in 35 countries