



**A problem shared is a problem
halved? Dementia: Learning
opportunities from Europe**

A Policy Brief

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Background

This policy brief will form part of a series of briefs on mental health, wellbeing and ageing, kindly supported by Pfizer Inc.

Introduction

Mr Brown is 72 years of age. He lives with his wife, in a small house near the sea. After 45 years of working in the construction industry, Mr Brown is enjoying retirement, he is however becoming increasingly concerned by his frequent lapses of memory and growing confusion. "Is this just part of the ageing process?" he muses. Mrs Brown has also observed a change in her husband's behaviour and demeanour, watching on with fear, as he struggles with his daily activities...

There are 7.3 million stories which start like Mr Brown's across the Member States of the European Union.¹ However beyond the first few pages, each story will evolve very differently. The incalculable loss, pain and suffering posed by dementia and its most common manifestation, Alzheimer's disease, will be pervasive throughout, yet for each individual their pathway of experience will follow its own unique course.

All stories though are situated in a local, regional and national context. How Member States respond through formal and informal systems and structures will invariably influence the individual's care continuum, for example, why is it that if Mr Brown lived in Scotland he would have an 80% chance of being informed of his diagnosis by a GP, compared to a rate of 23% in Spain?² There is thus a widespread disparity in the diagnosis, treatment and care of people with dementia across the Member States of the European Union.

If we are to strive for a common European goal of equality of access to care and treatment of all EU citizens, there are a number of fundamental questions that need to be addressed at the national and EU level.

This policy brief will explore some of those questions and ask why there are variations in how dementia is treated across the continuum of care in different EU Member States, with particular reference to diagnosis. It will also consider how we assess the efficacy of policy interventions at the Member State level and how policy-makers reconcile the competing demands of need, want and value for the public purse.

In light of this burgeoning challenge for EU Member States the second part of the policy brief will explore the current and the potentiality for an enhanced role of the European Institutions to help raise standards in dementia diagnosis, treatment, care and research across Europe. More broadly, this brief will posit there needs to be greater inter and intra collaboration at the European level.

¹ European Commission (July 2009) Communication on a European Initiative on Alzheimer's disease and other dementias

² Alzheimer Europe (June 2008) Dementia in Europe – The Alzheimer Europe Magazine

EU Context

Commensurate with population ageing the number of people with dementia across the EU is set to increase. Paradoxically it is as a result of our successful longevity, that we are now facing, as one British Minister described, as a 'Tsunami' of dementia.³

It is estimated that in 2006, 7.3 million Europeans (across the 27 Member States) between 30 and 99 years of age had some form of dementia. Within this group, more women (4.9 million) than men (2.4 million) are affected. It is expected that by 2050 the number of people with dementia in the EU will have grown to 15 million.

However many individuals with Alzheimer's disease and other forms of dementia remain undiagnosed in the EU. According to the available epidemiological data, the number of people affected is probably significantly higher than the official cited figures.⁴ It is also worth noting there will be variations in the rate of incidence and prevalence across different Member States.

In formulating and planning general policies and programs regarding older people, mental health and disabled or for dementia specific programmes, all policy-makers are faced with the daunting analytical task of assessing a multitude of projections. The challenge of projecting demographic and economic developments over the next 50 years is compounded by considerable uncertainty, for example on migration flows, the health status of the elderly or the incidence of disability.⁵

The question of how Member States respond to this impending, yet in certain instances, unquantifiable challenge is critical. With an anticipated increase of these diseases, it is imperative the potential consequences in terms of financial cost and sustainability are considered. The total cost of Alzheimer's disease and other forms of dementia in the EU 27 Member States was estimated at €130 billion, this included direct and unpaid care costs. This equates to €21,000 per patient and 56% of these costs were unpaid care costs.⁶ This compares to \$83.6 billion in North America and \$88.7 in Asia.

As a result of the escalating costs to our fiscal and social economies and the overwhelming increase in numbers, major structural changes for all countries are implied and need to be catered for - dementia necessitates quantitative and qualitative changes to our cultural, economic, social and political structures.

³ Phil Hope MP, (July 2009) National Dementia Research Summit

⁴ European Commission (July 2009) Communication on a European Initiative on Alzheimer's disease and other dementias

⁵ European Commission (2009), The 2009 Ageing Report

⁶ European Commission (July 2009) Communication on a European Initiative on Alzheimer's disease and other dementias

How do we assess the efficacy the policy interventions of Member States?

The baseline of policy interventions for all EU countries is to respond to the need for services of dementia at the population level. Indicators for this need will be based on the prevalence of dementia, projected prevalence rates and the current utilisation of services. Related to this will be costs and the respective country's eligibility criteria for services.⁷

Underlying these policy interventions, several commentators argue are a core set of policy principles which guide the formulation of dementia policy, notably in advanced welfare states.⁸ These include: early diagnosis, co-ordination of services at the local level, for the individual to remain in their home as long as possible and support for carers in order to achieve this.

The critical question therefore for policy-makers is what sort of interventions will best serve these principles?

If we are to assume certain member states are collectively united by these principles, there still remains no discernible consensus on just how public policy should respond.

There is a growing consensus across European networks that developing national action plans on dementia is the 'gold standard' of policy interventions. The EU Member States with action plans or variants of include: France, the UK⁹, Norway, the Netherlands and Italy.

The impetus for such actions derives from a range of actions and actors. These include: high level champions, as in the case of President Sarkozy in France and the growing prominence and weight of campaigning charities, this is particularly pertinent to the development of the National Dementia Strategy in England and the campaigning role of the Alzheimer's Society.

A key part of these action plans are often dementia specific health and social care programmes. However despite the obvious merits of such a targeted approach, the long-lasting 'efficacy' of such programmes remains unknown due to an underdeveloped research base.

Dementia specific actions or programmes are not in themselves a panacea, particularly if wider support systems and structures in the health and social care arena are not in place. For example, the introduction of memory clinics across several EU member states has been widely considered to improve rates of early diagnosis. However as the early French experience demonstrated, increasing the number of clinics did not in itself give rise to this, as there remained significant levels

⁷ Moise P et al (2004) Dementia Care in 9 OECD Countries: A Comparative Analysis

⁸ Marshall (1999), Riggs (2001) in Moise P et al (2004) Dementia Care in 9 OECD Countries: A Comparative Analysis

⁹ The National Dementia Strategy for England launched in February 2009, will be followed by strategies for Wales, Scotland and Northern Ireland

of inertia and reluctance on behalf of GPs to refer patients to the clinics.¹⁰ The third and latest action plan from France has tried to rectify this, adopting a more holistic approach to the thorny problem of early diagnosis. The plan promised a guiding framework for initial diagnosis and referral and a wider awareness raising campaign.¹¹

The French experience not only demonstrates the unintended consequences of policy interventions, but also highlights the changing policy focus towards dementia. The challenge of dementia necessitates quantitative and qualitative changes to our economic, social and political structures. Thus policy-makers are now starting to 'unpick' the cultural and social environment which frames dementia.

How do policy—makers reconcile need, want and value for the public purse?

In the context of limited public budgets, Governments will increasingly seek to target resources on outcomes that will produce the biggest 'return' for their objectives of public policy or on targeting those most deemed to be in need.¹² The shape and course of public policy will also be influenced by rising expectations towards health and social care and the political and public priority attached to particular 'good causes'.

At the present time, the mainstream discourse on the fiscal impact of dementia is generally framed in relation to cost and consumption.¹³ Indeed the widespread negative discourse on the growth of the ageing population more generally encapsulated in pejorative terms such as 'burden', 'problem', 'dependency' has invariably encouraged reactive policy-making at the expense of a more planned and preventative approach. Policy- interventions regarding older people generally or for dementia specifically are thus not widely represented as an 'investment' in future health and social care.

In the absence of any curative treatment for dementia, there is no widespread consensus on the priorities for resource allocation. This inherent conflict raises some intractable questions for policy-makers.

If it is possible to delay the onset of dementia for example, will that save money in the long-term? Or if Member States invest in drugs that halt the disease, people with dementia will have a normal lifespan and there will be a huge incentive for earlier diagnosis.

Indeed early diagnosis is gradually being recognised as providing significant fiscal, social and health benefits. As a recent paper in 2009 argued, if dementia is diagnosed early, the person with dementia and their carers have a greater opportunity to plan for their future and/or equip themselves with the help, support and treatments which may be available. This in turn will help delay or prevent

¹⁰ Lustman, F (2009) House of Lords dinner debate on dementia

¹¹ French National Action Plan (2008)

¹² Lloyd J (2008) Living and Caring for All

¹³ Alzheimer's Europe (2008) Dementia in Europe Yearbook

transitions into care homes, which are widely known to be costly to national economies and/or families.¹⁴

The research behind the paper aimed to provide an evidence base to demonstrate the potential public and private savings of early diagnosis. This was achieved through studying delayed admissions to care homes in England as a result of early diagnosis in the form of the commissioning of memory services. The model suggested the new services would cost around £220 million extra per year, but the estimated savings if 10% of care home admissions were prevented would by year ten be around £120 million in public expenditure (social care) and £125 million in private expenditure (service users and their families), a total of £245 million. Under a 20% reduction, the annual cost would within around six years be offset by the savings to public funds alone.

The authors argue early diagnosis coupled with effective early interventions and service structures are essential for 'cost' effectiveness. Another recent paper on the social and fiscal impacts of early identification and treatment of Alzheimer's disease, using Wisconsin as a model, supports this.¹⁵ The analysis considered two types of interventions following diagnosis: patient drug treatment and caregiver-support programs. Each interventions provided positive net savings, with the greatest benefits achieved using a combination of both. Beyond the net savings, there were also positive social outcomes, including slower disease progression and improved quality of life for the patients' families and caregivers.

Thus early intervention is slowly being recognised as being cost and socially advantageous, the 'spend to save' adage. With a growing research base to support this approach, more Member States may start to look beyond the short term and consider early intervention and diagnosis as a sensible investment. In the early stages, individuals require only limited care and assistance, in contrast to the expensive full-time care required by many people in the moderate to late stages. Similarly delaying or slowing the progression of these diseases will reduce the potential negative consequences for carers and facilitate the individual to stay in their own home as long as possible.

However, if we invest in drugs that slow the rate of progression delaying the late stages of the disease, there will be less demand for nursing homes. Though, if drugs prolong the late stages, there will be more demand, and invariably both scenarios will necessitate an increased contribution by unpaid carers.¹⁶

The prevention of dementia through modifiable interventions is another critical piece of the dementia policy jigsaw which arguably holds great promise.¹⁷ There are a number of factors that have been associated with the incidence of Alzheimer's

¹⁴ Banerjee S, Wittenberg R (2009) Clinical and cost effectiveness of services for early diagnosis and intervention in dementia

¹⁵ Weimer D, Sager M (2009) A cost benefit analysis of using of the social and fiscal impacts of early identification and treatment of Alzheimer's disease, using Wisconsin as a model

¹⁶ Brodaty H (2008) EU French Presidency Conference on 'The Fight against Alzheimer's Disease and Other Related Disorders'

¹⁷ Prince, Livingston, Katona (Feb 2007) Mental health care for the elderly in low-income countries: a health systems approach, World Psychiatry

disease. Some of these preventative factors include: a healthy diet, promoting physical and cognitive activity and controlling cardiovascular risk factors such as diabetes, high cholesterol and hypertension.¹⁸

Modifiable risk factors also underscore the importance of public information campaigns and public health promotion to raise awareness and education on risk reduction. It is also important to note many of these preventative measures are also likely to improve general health. Initiatives of this sort are significant, because if we could delay the onset of dementia for two years, this would reduce the prevalence by 20%, if we could delay it by five years, it would halve the prevalence.¹⁹

However preventative strategies remain a relatively overlooked area of dementia policy. This may be attributable to the long-term investment required and a relatively under-developed research base (though this will be significantly improved by the current pan-European EuroCoDe project).²⁰ The need for more research into primary preventive interventions was highlighted at the UK Ministerial Dementia Research Summit in July of this year, increased funding in this field was highlighted to be a priority.²¹

Indeed without additional support and funding for research on dementia, potentially promising and cost effective interventions, such as research on modifiable risk factors, will remain on the margins of policy development.

There is a growing consensus across Europe that advancement in research will not occur without a significant increase in expenditure. In many EU Member States dementia research is woefully under funded, though in Germany and more recently in France there have been significant resources committed to research and development. In 2008 in France €29 million of spending was committed to the establishment of a Foundation for Scientific Research, which was aimed to stimulate and coordinate research into Alzheimer's disease in France.²²

Indeed dementia research is arguably the 'sick man of Europe' with investment falling consistently behind cancer and heart disease research. Despite the prevalence and cost of dementia, dementia research has consistently been sidelined in not only political, but public priorities. In the UK for example, the Government spends £32 million a year on dementia research, which is only one eighth of what the Government spends on cancer research. Clearly this is yet another area where the conceptualisation and stigma attached to dementia has not served it well in terms of the 'public sell'.

Given the demographic changes and the predicted increase in the prevalence of dementia, it should make sound economic sense to invest more heavily in research at the present time, investing 'today for tomorrow'. One medical research association found that for every dollar invested in dementia there was a 150% return.²³

¹⁸ Australian Government (2005) Response to the Productivity Commission on Ageing

¹⁹ Brodaty H (2008) EU French Presidency Conference

²⁰ EurCoDe (2006), http://ec.europa.eu/health/ph_projects/2005/action1/action1_200510_en.htm

²¹ Ministerial Dementia Research Summit (July 2009)

²² French National Action Plan (2008)

²³ Brodaty H (2008) EU French Presidency Conference

An emerging role for the European Union Institutions?

All EU Member States need to respond to the challenge of dementia, how they choose to prioritise their resources' and what constitutes 'best value' for the public purse however remains a matter of debate. While traditionally health and social care are seen as the exclusive preserve of Member States, increasingly given the continuous convergence of the health systems across the EU, one could argue there could be an enhanced and increased role for the European Union Institutions.

The European Community, for example can make direct and indirect interventions in healthcare, as acknowledged in Article 152 of the Amsterdam Treaty.²⁴ The range of mechanisms and instruments available include: standardisation of indicators, stimulation of exchange on evidence-based developments and best practises, promoting quality benchmarks and support for networking for greater coordination among different national and international groups.²⁵ In recent years a growing concern over the impact of demographic change and an ageing EU population, coupled with the drive of the French Presidency has propelled dementia to the forefront of EU actions and initiatives.

The programme of community action in the field of public health (2003-2008) included specific reference to dementia. In particular the need for information, definition of indicators, cost of illness, social support and preventative strategies. More recently in July 2009, the Commission adopted a Communication pledging EU support for national efforts in four key areas: prevention, coordinating research across Europe, promoting best practice for treatment and care and developing a common framework to address ethical questions.²⁶

The potential benefits of an enhanced role for the European Union Institutions

Thus the EU Institutions seem to be carving themselves an enhanced role in the policy field of dementia, the question remains however, if this increased intervention is necessary or indeed welcome?

Looking beyond the superficial justification that global problems require global solutions, there are a number of persuasive arguments to support increased EU intervention.

Now more than ever, it is important to highlight the relevance of the European Social Model.²⁷ Faced with demographic ageing and delineating public resources, one could argue European Governments should avoid retreating into an attitude of

²⁴ The treaty states: "a high level of human health protection shall be ensured in the definition and implementation of all policies and activities, EU Commission, 2003.

²⁵ European Foundation for the Improvement of Living and Working Conditions (2004) Sector Futures: Policy and Actions for a Health Europe

²⁶ European Commission (2005) Work Plan for 2005

²⁷ The European Social Model is a vision of society that combines sustainable economic growth with ever-improving living and working conditions.

national protectionism and instead invest in a co-ordinated social model based on solidarity between citizens and regions and involving all political and civil actors.

Similarly as we move towards a more rights based approach in the treatment of individuals with dementia, the EU is ideally situated to promote, exchange and stimulate debate on equality, anti-discrimination and rights. The EU Charter of Fundamental Rights has enshrined the right to dignity (Article 1) and the right of the elderly to lead a life of dignity and independence and to participate in social and cultural life (Article 25).²⁸ However at the moment, many individuals with dementia are denied the chance to grow old with dignity. It is thus imperative the European Union Institutions encourage Member States to promote and protect the fundamental rights of people like Mr Brown (as referenced in the introduction).

We are also living in a growing interconnected and interdependent world. Given the migration and immigration between and into EU member states, there is intrinsic value attached to connecting, learning and sharing from our European neighbours. Collectively policy-makers need to think about increased diversity linked to immigration of ethnic minorities everywhere in Europe over successive generations, who now form part of the EU's ageing population.

With regard to migration, there is also a need for the EU to promote genuine free movement for all citizens, regardless of age. At present given the vagaries of Member States respective health and social care systems, if Mr Brown did opt to retire abroad with dementia, for example in Spain, he may have to pay his health and social care costs. In Spain only low-income families receive financial support. There is a pressing need to have clarity at the EU level over applicable health rights and responsibilities, the EU Directive on cross-border health care is hoped to address some of these issues.

Perhaps the most widely recognised and endorsed role of the EU in the field of dementia is in the field of research. There is a growing consensus on the value of pooling and coordinating research activity and agendas on dementia. The EU is perceived by many to be instrumental in supporting dementia research initiatives to produce new treatments, preventions and possible cures for the set of diseases.

The Sixth and Seventh Framework has been critical in this respect. The Sixth Framework Programme (FP6) provided funding of €111 millions to European projects in the area of neurodegenerative diseases. The aim of this research is to understand Alzheimer's disease and rarer neurodegenerative disorders. The health research budget for the Seventh Framework Programme (FP7) increased from €2.5 billion to €6.1 billions over the period 2007-2013. The focus of FP7 is to reinforce collaborative research and the networking of European research groups, improve public-health research and drive international cooperation. This activity included the

²⁸ Charter of Fundamental Rights of the European Union.
http://www.europarl.europa.eu/charter/pdf/text_en.pdf

establishment of the Innovative Medicines Initiative (IMI)²⁹ to reinforce research on the prediction of the suitability, safety and efficacy of drugs and treatment.³⁰

More recently there has been a growing call across the EU research community for a Joint Programming approach. In July of this year, the vision moved one step closer, with the Commission presenting a proposal for a pilot Joint Programming initiative on combating neurodegenerative diseases, in particular Alzheimer's disease.

This approach involves Member States engaging voluntarily in the definition, development and implementation of a common research agenda. The merits of Joint Programming are numerous, including: avoiding unnecessary duplication, pooling and coordinating the efforts of European basic and clinical researchers in the field and increasing the efficiency of effectiveness of national and EU research and development spending.

Priorities for Action

It is evident that until there is a cure for Alzheimer's disease and other forms of dementia, it will remain a significant and growing public health challenge. With regard to shaping public policy to adequately address the needs of people with dementia and their families and provide a suitable infrastructure of support, there are no easy answers or a proven roadmap of success. There are however good practices emerging in different countries across the EU with regard to diagnosis, treatment and care, though at the present time they are not being adequately shared throughout the Union.³¹

While each country retains jurisdiction in these areas, there is arguably an emerging role for the EU to foster, promote and stimulate collaboration between Member States.

Below are some recommendations on how with a common commitment the EU and its Member States can push dementia to be at the forefront of public health and social policy development and research:

-Recognition at EU level of the fundamental human rights of people with dementia with regard to a right to a diagnosis, access to care to a minimum standard, appropriate, suitable and timely treatment and assured protection of autonomy and dignity. For example this could be included in the EU Charter of Fundamental Rights.

-The European Pact for Mental Health and Well-Being could be used to provide a framework for awareness-raising activities and the exchange of good practices for Alzheimer's disease and other dementias. Prevention of

²⁹ The IMI was established as a public-private partnership between the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Commission

³⁰ Hallen M, , Health Directorate, DG Science and research, European Commission (2008) French Presidency Conference on Dementia.

³¹ Council of the European Union (2008), Council conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease.

Alzheimer's disease and other dementias could be another strand complementing the Pacts focus on mental health well being and disorders.³²

-To deliver on the European Council conclusions to develop by means of the Open Method of Coordination, quality frameworks for medical and care services for people with dementia. This should include developing appropriate mechanisms for ensuring availability of timely support with regard to the short fall of long-term care.

- For the EU to call upon Member States in the form of a Communication to present National Action Plans to improve the availability of medicines/treatment for age related illnesses, including Alzheimer's disease and other forms of dementia. Also for Member State level initiatives that encourage the innovation of medicines to tackle age related illness.

- For the EU to promote awareness and understanding of dementia. To invest in an awareness raising campaign on dementia to educate and inform professionals and the public. This campaign will also need to address the wider discrimination, prejudice and stigma associated with mental health and older people's issues more generally. A 'European Year of Dementia' should be introduced.

-For the EU to continue to promote cross-cutting and interdisciplinary research at the UK and EU level – Co-ordinating collaboration on dementia would offer substantial benefits, including greater coherence and synergy in research and understanding, the opportunity for developing new comparative methodologies and databases (success of the European database on Huntington's disease for example) standardised instruments and the harmonisation of data.

Conclusions

It is evident that across the EU and in certain EU Member States dementia is emerging as a policy priority. While there are commonalities in approach to the diagnosis, treatment and care of people with dementia in Member States, each system and structure is distinct.

The scale and size of the respective task may be different, but the intractable issues that now loom large are essentially the same. With an ageing population across Europe, no country can afford to remain indifferent to the profound challenges dementia raises with regard to public health, social protection and research.

While each country retains jurisdiction in these areas, there is arguably an emerging role for the EU to foster, promote and stimulate collaboration and progress through its legislative and non-legislative actions and initiatives.

As national policy-makers grapple with the thorny questions of policy priorities and limited public resources, they may look beyond their borders to see just how their EU

³² Council of the European Union (2008), Council conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease.

neighbours are faring. The EU as an institution is ideally situated to facilitate this, promoting greater collaboration, harmony and unity between EU Member States. We may not have reached the stage yet of all Member States, vying to 'keep up with the Joneses', but for the future of couples like Mr and Mrs Brown, we can only hope.