



# The European Dementia Research Agenda

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ILC–UK  
11 Tufton Street  
London  
SW1P 3QB  
Tel : +44 (0) 20 7340 0440  
[www.ilcuk.org.uk](http://www.ilcuk.org.uk)

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## Foreword

It is a sad fate that as a result of our enhanced longevity, dementia syndrome and the large number of underlying brain pathologies – Alzheimer’s disease, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and other dementias – are set to blight the landscape and lives of individuals and families across the world. Dementia presents an immediate and profound global challenge to us all. There is no longer just a moral and social argument for prioritising dementia; the economic imperative is now overwhelming and the implications for health, social care and research are evident.

As well as the considerable challenge of caring for and treating individuals with dementia, there is also the growing question of research and the need for enhanced investment in an area, which has been historically sidelined in public and political priorities. Despite the fact that the 21st century is widely attested to be the era of neurodegenerative diseases, the prevalence of such diseases has not been matched by comparable government investment in scientific research in this field. Funding for dementia research has consistently fallen behind cancer and heart disease. Government and charitable spending on dementia research is 12 times lower than on cancer research. For every person with cancer, £295 is spent each year on research, for dementia, that figure is just £61 (Luengo-Fernandez et al, 2010).

Against this backdrop, an expert working group meeting in the European Parliament was convened in November 2010 to discuss the dementia research agenda at the Member State and EU level. The discussions and recommendations from the meeting form part of the basis of our report. Alongside data on the growing scale of dementia across Europe and the burgeoning economic, health and social care costs. I do hope this report serves as a platform for future action and highlights the priority issues we should all try to help take forward.

I would also like to thank all those who took part in the working meeting for their enthusiasm, commitment and for travelling so far; your presence was greatly appreciated.



Baroness Greengross OBE  
Chief Executive, ILC-UK





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# Executive Summary

Commensurate with population ageing the number of people with dementia across the EU is set to increase. If current trends continue, then the over 65s in the EU will increase from 85 million in 2008 to 151 million by 2060. The escalating economic, health and social care costs necessitate fundamental changes in policy interventions for Member States and EU Institutions. A recent report by Standard and Poor's argues that developed countries have between four to six years to address the issues of long term care and dementia care, before our economies crumble under the strain.

In light of this contemporary challenge for public policy, on the 16<sup>th</sup> November 2010 a high level group of experts in dementia research convened at the European Parliament, to discuss the dementia research agenda. The purpose of this report is to present the opinions, views and knowledge expressed at the meeting and to serve as a platform for further actions and initiatives at the EU and Member State level. This forms the latter section of the report. The first part of the report aims to set the scene to the dementia research environment, by exploring the scale of the challenge ahead, the current funding environment and recent EU policy developments in this regard.

Despite the fact that the 21st Century is widely attested to be the era of neurodegenerative diseases, the prevalence of such diseases has not been matched by comparable government investment in scientific research. Funding for dementia research has consistently fallen behind cancer and heart disease in not only political, but public priorities, although the incidence of dementia is greater than both of these.

However there is some evidence that dementia research is rising from the lacunae. At the Member State level, dementia research has been at the fulcrum of certain national action plans on dementia such as in France or as is the case in the UK, has been pushed to the forefront through dedicated Ministerial meetings and advisory groups. However as yet, there is still a paucity of evidence on public, private and charitable funding streams across the respective Member States. The catalyst for increased EU actions and initiatives arguably derived from the French Presidency conference on 'The fight against Alzheimer's and related disorders', held in October 2008. This conference paved the way for the Council's conclusions in December 2008 on public health strategies to combat neurodegenerative diseases associated with ageing, in particular Alzheimer's disease. Greater collaborative and transnational working also received a much needed boost with the recent European pilot initiative for combatting neurodegenerative diseases under the Commission's Joint Programming Initiative.

Yet despite these recent efforts and initiatives, there was a strong sense from delegates attending the meeting on the 16<sup>th</sup> November that dementia research requires further policy interventions at the Member State and EU level. In this report, we highlight the need for increased investment and support across the dementia research spectrum from basic and clinical research, to translational research, to ensuring research is applied and delivers tangible improvements in health and social care. From these conclusions, the ILC-UK have developed specific 'Calls to Action' for the European Commission, the European Parliament, Member State Governments and other key actors in the dementia field. These include: calling on the European Commission to prioritise dementia research under Framework Programme 8; to develop a European Charter to increase the participation of people with dementia in clinical trials; share best practice and examine current obstacles; organise an EU level conference on dementia research and develop a distinct section on dementia research on the official public health portal of the European Commission to improve public health provision.



<b>Conclusions</b> →	<b>Calls to Action</b>
<p><b>Priorities for Basic/Clinical Research</b></p> <ul style="list-style-type: none"><li>• Facilitation of fundamental/basic research on Alzheimer’s disease.</li><li>• Greater research into the impact and how to manage co-morbidities with Alzheimer’s disease and other dementia syndromes.</li><li>• Greater research into rarer dementias.</li><li>• Increasing the number of neuropathologists in clinical research.</li><li>• Supportive infrastructure and technologies.</li></ul> <p><b>Priorities for Translational Research</b></p> <ul style="list-style-type: none"><li>• Improved presymptomatic markers to improve early diagnosis.</li><li>• Increasing and speeding up clinical trial enrolment is a priority.</li><li>• Increase funding and capacity for translational research and more multidisciplinary programmes.</li></ul> <p><b>Priorities for Co-ordination, Co-operation and Networking</b></p> <ul style="list-style-type: none"><li>• Build more co-operative networks across Europe and capacity within research institutions.</li><li>• Closer cooperation between industry, regulators and payers to agree clinical priorities and research benchmarks earlier in the process.</li><li>• Greater links between industry, academia, the public and charity sector.</li><li>• Creation of a stronger dementia research environment.</li></ul>	<p><b>In response the ILC-UK calls on the European Commission to:</b></p> <ul style="list-style-type: none"><li>• Organise an annual conference on dementia research.</li><li>• Prioritise dementia research under Framework Programme 8, given the growing burden and financial, health, social and human cost of dementia across Europe.</li><li>• Consider a collection of country reports on dementia research funding.</li><li>• Develop a European Charter to increase the participation of people with dementia in clinical trials, share best practice and examine current obstacles.</li></ul> <p><b>The ILC-UK calls on Governments of the Member States to:</b></p> <ul style="list-style-type: none"><li>• Create national centres of excellence in dementia research.</li><li>• Develop networks and relationships between researchers from the public and private sphere.</li><li>• Ensure parity in funding for dementia research in line with other chronic disease and the disease burden.</li><li>• Creation of a stronger dementia research environment.</li></ul>



Conclusions →	Calls to Action
<p><b>Delivering Health and Social Care</b></p> <ul style="list-style-type: none"> <li>• Develop Member State’s health service infrastructure to enhance research infrastructure and increase collaborative working between academics, clinicians, researchers, the care industry, patients and their families.</li> <li>• Greater awareness, education and training on dementia and the importance of research across the primary care setting, particularly with regard to general practitioners.</li> <li>• More research commissioned on the disparity of care received by individuals with dementia and without dementia in hospital settings.</li> <li>• Greater integration of care and research to be prioritised at the Member State level.</li> <li>• More carer-centred research.</li> <li>• More research commissioned on non-pharmacological interventions particularly in residential and nursing care.</li> </ul>	<p><b>The ILC-UK calls on Governments of the Member States to:</b></p> <ul style="list-style-type: none"> <li>• Ensure the implementation and adequate resourcing of comprehensive national strategies to address all aspects of dementia.</li> <li>• Increase the number of health care professionals trained in dementia.</li> </ul> <p><b>The ILC-UK calls on NGOs, clinicians, industry and academia to:</b></p> <ul style="list-style-type: none"> <li>• Work with professional bodies that represent, regulate and are responsible for GPs and other health care professional training to encourage more Continuing Professional Development in dementia and the exchange of best practice.</li> </ul>
Conclusions →	Calls to Action
<p><b>Equality and Human Rights</b></p> <ul style="list-style-type: none"> <li>• The rights of individuals with dementia need to be firmly embedded in the human rights agenda.</li> </ul>	<p><b>The ILC-UK calls on the Members of the European Parliament and Member States to:</b></p> <ul style="list-style-type: none"> <li>• Support the drafting and adoption of a United Nations Convention on the Human Rights of Older Persons.</li> </ul>
Conclusions →	Calls to Action
<p><b>Raising Political and Public Awareness</b></p> <ul style="list-style-type: none"> <li>• Explore the level of public support and demonstrate the value of dementia research to a wider audience.</li> <li>• Dementia must be viewed as a public health priority and there needs to be greater information on research and clinical developments for the general public.</li> </ul>	<p><b>The ILC-UK calls on the European Commission to:</b></p> <ul style="list-style-type: none"> <li>• Develop a distinct section on dementia research on the official public health portal of the Commission.</li> <li>• Explore level of public support and demonstrate value of dementia research to a wider audience through a targeted Eurobarometer survey.</li> </ul>





# Introduction

This report brings together recent research on the scale, cost and national and EU responses to dementia alongside the presentations, discussions and ideas, which emerged from an expert working group meeting on dementia research, held on 16<sup>th</sup> November 2010 in the European Parliament.

The first part of the report outlines the scale of dementia in Europe, including data on the current and future predictions of the prevalence, incidence, disease burden and mortality rates across the EU. It also considers the growing economic, social and human cost of dementia. National dementia research initiatives and EU activities are explored to demonstrate the diversity of approaches and the priority attached to dementia research in the respective EU Member States.

The latter section of the report provides a summary of the presentations and identifies some of the key themes discussed at the expert working group meeting on dementia research. Chris Davies MEP, the Environment and Public Health spokesperson for the Alliance for Liberals and Democrats for Europe (ALDE) political group kindly agreed to host and co-chair the meeting with Baroness Greengross. The meeting was attended by 33 leading experts from charities, industry, public bodies, universities and voluntary organisations from across Europe.

The overarching aim of the meeting was to support the development of a more clearly prioritised European research agenda in the field of dementia. It focussed on ways to support the current science base and sharpen its impact. The delegates were asked to consider a number of questions, including:

- What are the top priorities for new research in Europe?
- What are the barriers to effective research and how can these barriers be overcome?

The meeting also focused on the recent EU initiatives in the field of Alzheimer's disease, specifically the Joint Programming Initiative and how to best co-ordinate research activities and actions between EU Member States. The final part of the meeting was dedicated to formulating some conclusions and priorities for action. From these discussions the ILC-UK have developed specific 'Calls to Action' for the European Commission, the European Parliament, Member State Governments and other key actors in the dementia field.

Speakers were given an opportunity to comment on their presentations in the report, to ensure their comments were accurately represented. The views and opinions expressed in the presentations are those expressed solely by the presenter. It should also be noted the views and opinions contained in the latter part of the report are those expressed by the delegates and speakers attending the meeting in their personal capacity. The 'Calls to Action', as mentioned above, are strictly those of the ILC-UK and should not be attributed to any of the speakers or delegates directly.

# Part 1 – The Policy, Research and Political Context

## The Scale of Dementia in Europe

### What is dementia and what does it mean for the individual?

Dementia is an “acquired syndrome of decline in memory and other cognitive functions” (OECD, 2004) and has been described as signalling “the loss of intellectual abilities of sufficient severity to interfere with social or occupational functioning” (American Psychiatric Association, cited in Chicot et al, 2002). The most common form of dementia is Alzheimer’s disease (OECD, 2004; Royal College of Psychiatrists, 2009), which is responsible for up to 80% of dementia cases (Alzheimer’s Association, 2009) and is the fourth most common cause of disease burden in high income countries (Alzheimer’s Disease International, 2009).

Dementia is a progressive disease (WHO, 2006; OECD, 2004), which in the early stages results in short term memory loss, difficulty in making decisions, and difficulty recognising time, dates and surroundings (OECD, 2004; WHO, 2006). As dementia progresses, people may become very forgetful, have speech problems, become easily disoriented, have disturbed sleep and become unable to function independently (WHO 2006; OECD, 2004). In the later stages of dementia, a person may also have problems eating and communicating and end up confined to a wheelchair or bed (WHO, 2006). Dementia is ultimately a terminal illness, which runs contrary to the widely held belief that dementia is a memory disorder, although this is one of the hallmark symptoms. This common misconception by the general public and indeed by some in the medical profession has significant repercussions for the individual’s access and rights to appropriate palliative care (Elton, 2009).

### An ageing population

Demographic change and medical and technological advances have heralded a new dawn in the population landscape with a wave of ageing across the developed and indeed developing world. The rate of growth is rapid with both overall numbers and proportions of older people rising rapidly. The population of Europe is ageing with significant increases in the over 65 population because of increasing life expectancy, and a decrease in younger age groups due to falling fertility, and falling inward migration (Eurostat, 2008). If current trends continue, then the over 65s in the EU will increase from 85 million in 2008 to 151 million by 2060, of which the oldest old (over 80) are projected to increase from 22 million in 2008 to 61 million in 2060 (Eurostat, 2008).

Demographic change is resulting in an increase in the “dependency ratio”, which is the number of working age people versus non-working age people e.g. pensioners and children. Current demographic trends are resulting in an increase in the number of older people many of whom are pensioners. If these trends continue, then in the future many European countries will see each person of working age supporting more non-working age people than in the past. This has implications for publicly funded services, particularly healthcare, social care and pensions.

# Prevalence, incidence, disease burden and mortality

## Prevalence

The steady and future growth of our ageing population will lead to a dramatic increase in the number of people with dementia. The World Alzheimer Report 2009 reports that there are currently 35.6 million people with dementia with the numbers set to double every 20 years to 65.7 million in 2030 and 115.4 million in 2050 (Alzheimer's Disease International, 2009). EU funded projects EuroDem and EuroCoDe estimate the number of people with dementia in 2006 in the EU 27 to be between 6.8 and 7.3 million, of which 2.3 to 2.4 million are men and 4 to 4.9 million are women<sup>1</sup>.

However, it should be noted, 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 official figures suggest, there are variations in the rate of incidence and prevalence across different member states (Bamford, 2010).

## Incidence

Incidence, which is the rate of new cases occurring in a population in a given time period, is generally considered a more effective measure of disease risk. Almost all incidence studies report a positive association between age and incidence rates of dementia. In some European and Asian studies the incidence rates of Alzheimer's disease were found to be higher in women than in men. The EuroDem studies showed significant gender differences in the incidences of Alzheimer's disease after 85 years of age, with a higher risk in older women than men. However several cohort studies report no difference in incidence rates between men and women, so this positive association remains widely open to debate (Kokmen et al 1996). Dementia predominantly affects the over 65s (Royal College of Psychiatrists, 2009) with an estimated 6.4% of people over the age of 65 being affected (Lobo et al, 2000) and around one in five people over 80 being affected (Royal College of Psychiatrists, 2009). After the age of 65, the risk of dementia doubles for every additional five years of life (WHO, 2006).

## Disease Burden

Dementia is considered to be among the most disabling of all chronic diseases. The middle to late stages of the disease, in particular, signal a loss of autonomy, physical and cognitive function and independence for most individuals affected. According to the most recent Global Burden of Disease report, as cited in the World Alzheimer Report, dementia contributes to 0.8% of all Disability Adjusted Life Years (DALYs) worldwide. 1.6% of Years Lived with Disability and just 0.2% of Years of Life Lost (Alzheimer's Disease International, 2009). As dementia is a disease which primarily affects the older population, the proportionate contribution is considerably higher among those aged 60 and over, accounting for 4.1% of DALYs, 11.3% of Years Lived with Disability and 0.9% of Years of Life Lost (Alzheimer's Disease International, 2009).

Dementia rarely arises in isolation and can often be accompanied by other physical health problems such as cardiovascular disease, and mental health problems such as depression

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<sup>1</sup>See annex one for detailed breakdown.

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(WHO, 2006; OECD, 2004). Swiss research has shown that patients with dementia have worse functional and nutritional status than patients without dementia suffering the same comorbidities (Zekry et al, 2007).

## **Mortality**

While dementia is more commonly associated with disability and cognitive impairment, it is slowly being recognised as an underlying cause of death. The dementia specific mortality rate has been found to be twice the rate of people without dementia, controlling for co-morbidities and socio-demographic factors. Indeed, chronic non-communicable diseases are now the major cause of death among older people in both the developed and developing world (WHO, 2005). Coined the “epidemiologic transition”, a phrase used to refer to a long-term change in leading causes of death, from infectious and acute to chronic and degenerative conditions, developing countries are currently in various stages of the transition (Kinsella and He, 2009).

## **The Economic, Human and Social Cost of Dementia**

The impact of dementia presents a challenge to all EU Member States. At the present time, the mainstream discourse on the fiscal impact of dementia is generally framed in relation to cost and consumption (Alzheimer’s Europe, 2008). Policy interventions on dementia are thus not widely represented as an ‘investment’ in 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.

Dementia has wide-ranging direct and indirect health, human and social care implications including:

- Direct medical costs such as medication, nursing/medical interventions, which are usually paid for by state funded healthcare;
- Direct non-medical costs such as formal care and transportation for the patient, which can be paid for by the state and/or families of people with dementia;
- Indirect costs such as productivity loss, loss of earnings and withdrawal from the workforce by family members, friends or partners caring for a relative with dementia.
- Other challenges include:
  - Accurate and timely diagnoses;
  - Provision of information and support to families caring for a relative with dementia;
  - Unpaid carers as result of their caring responsibilities subject to financial hardship, social isolation and mental and physical health problems;
  - Emergency admission (short-term or long-term) of dementia patients to care homes following break-down of unpaid care.

While dementia can be treated, it cannot be cured (OECD, 2004; WHO 2006). Treatment includes medication and non-medical interventions. Medication includes cholinesterase inhibitors which temporarily decelerate cognitive decline in many Alzheimer’s patients and other drugs which treat psychological symptoms of dementia such as depression, anxiety and agitation (WHO, 2006). Non-medical interventions for people with dementia include “brain exercises” (Royal College of Psychiatrists, 2009) and providing carers with education, support

and information (WHO, 2006). The biggest cost for dementia patients is their care, most of which takes the form of unpaid care provided by family, friends or partners.

The European Commission (2009) estimate that dementia costs the EU (27 Member States), €130 billion a year including direct and indirect costs. Wimo and colleagues (2006) used cost of illness studies from different countries to estimate the average direct cost per dementia patient in the EU (EU 15 before enlargement) in 2003 to be \$10,985. An OECD study broke down costs even further and found the cost of Alzheimer's disease in several European countries to be as follows:

#### **Cost per AD case in US\$ (year 2000 purchasing power parity)**

	<b>France (1993)</b>	<b>Spain (1998)</b>	<b>Sweden (2000)</b>
Direct medical costs	\$10,055	\$2,144	\$10,480
Direct non-medical costs	\$6,826	\$2,565	\$19,065
Indirect costs	\$7,200	\$15,294	\$4,990
<b>Total</b>	<b>\$23,542</b>	<b>\$19,529</b>	<b>\$34,365</b>

Source: Dementia and Care in 9 OECD countries (OECD, 2006)

## **Dementia Research: National Responses**

National responses to dementia research do not follow a single model and are instead rather varied in terms of funding, organisation and participation. Most are a mixture of public and private involvement and funding, which includes government ministries, universities and other public research institutes, non-profit organisations and the private sector.

### **United Kingdom**

A National Dementia Strategy was launched in England in 2009 that included a commitment to promoting dementia research. A ministerial summit on dementia research followed, which was co-organised by the Department of Health<sup>2</sup> and the Medical Research Council<sup>3</sup>. The aim of the summit was to bring together experts and key stakeholders to agree on the key priorities for dementia research<sup>4</sup>. Following on from the summit, a ministerial working group was established to look at next steps and formulate a future road map for dementia research.

At the present time, funding for dementia research in the UK comes from a range of agencies including research councils, such as the Medical Research Council (MRC), and research agencies from the Department of Health and its devolved administrations, such as the National Institute for Health Research<sup>5</sup> (NIHR) and charities.

<sup>2</sup> <http://www.dh.gov.uk/en/index.htm>

<sup>3</sup> <http://www.mrc.ac.uk/index.htm>

<sup>4</sup> For more information, see the ILC-UK report of the Dementia summit at: [http://www.ilcuk.org.uk/files/pdf\\_pdf\\_102.pdf](http://www.ilcuk.org.uk/files/pdf_pdf_102.pdf)

<sup>5</sup> <http://www.nihr.ac.uk/Pages/default.aspx>

## France

In France, dementia research comes under the French national plan on Alzheimer's "Plan Alzheimer 2008-2012"<sup>6</sup>, which President Sarkozy unveiled in February 2008. The plan included €200 million over five years for research through the Creation of a Foundation for Scientific Cooperation on Alzheimer's disease. Examples of research projects funded by the Foundation in 2009 include: plasma dosage of amyloid peptides for the diagnosis of Alzheimer's disease; psychopathological risk factors present when mild cognitive difficulties lead to dementia; and evaluation of medical and economic consequences of different strategies of Alzheimer's disease prevention.

## Germany

In Germany, there are several private and public dementia research initiatives including the "Dementia Competence Network"<sup>7</sup> supported by the Ministry of Education and Research which aims to bring together outstanding players in research and medical care (BMBF.de, 2010). Projects funded by the network cover topics such as epidemiology and early diagnosis and GP care of dementia patients with multiple morbidities.

In March 2008, the German Centre for Neurodegenerative Diseases (DZNE)<sup>8</sup> was established. The DZNE consists of a core centre in Bonn and six other partner organisations based in Rostock/Greifswald, Magdeburg, Göttingen, Witten-Herdecke, Tübingen and Munich, and its main focus is on translational research, namely translating research into therapeutic practice. The University of Tübingen's Hertie Institute for Clinical Brain Research<sup>9</sup> established in 2000 also looks into dementia including Alzheimer's disease. In addition, a privately funded initiative Alzheimer's disease research initiative "Alzheimer Forschung Initiative"<sup>10</sup> was founded in 1995 and has funded over 60 projects with €3.7 million received in donations.

## Spain

Research into dementia in Spain comes under the neurodegenerative diseases strand of the national plan on neuroscience managed by the National Centre for Research into Neurological Disease (CIEN<sup>11</sup>), which comes under the control of the Ministry of Science and Innovation. In 2008, the Spanish Ministry of Health and the non-profit Queen Sofia Foundation<sup>12</sup> jointly established an Alzheimer's disease research centre as part of the "Alzheimer's project". In 2009, CIEN and the Institute of Health Carlos III<sup>13</sup> (Spain's public health research institute) joined forces with the Queen Sofia Foundation to create a research unit dedicated to Alzheimer's disease and related conditions<sup>14</sup>. In addition, the Queen Sofia Foundation and the Pasqual Maragall Foundation for Research on Alzheimer's disease<sup>15</sup> have launched a joint initiative to make 2011 the "year of Alzheimer's research"<sup>16</sup> in order to

<sup>6</sup> <http://www.gouvernement.fr/gouvernement/plan-alzheimer-2008-2012-l-effort-se-poursuit-en-2010> (in French)

<sup>7</sup> <http://www.kompetenznetz-demenzen.de> (in German)

<sup>8</sup> [http://www.helmholtz.de/en/helmholtz\\_centres/zentrum/detailansicht/german\\_centre\\_for\\_neurodegenerative\\_diseases\\_dzne/](http://www.helmholtz.de/en/helmholtz_centres/zentrum/detailansicht/german_centre_for_neurodegenerative_diseases_dzne/)

<sup>9</sup> <http://www.hih-tuebingen.de/index.php?id=667&L=1>

<sup>10</sup> <http://www.alzheimer-forschung.de/> (in German)

<sup>11</sup> <http://www.fundacioncien.es/home.asp> (in Spanish)

<sup>12</sup> <http://www.fundacionreinasofia.es/index-ides-idweb.html> (in Spanish)

<sup>13</sup> <http://www.isciii.es/> (in Spanish)

<sup>14</sup> [http://www.fundacionreinasofia.es/proyectoalzheimer/visita-nueva/common/Actividades\\_Proyecto\\_Alzheimer.pdf](http://www.fundacionreinasofia.es/proyectoalzheimer/visita-nueva/common/Actividades_Proyecto_Alzheimer.pdf) (in Spanish)

<sup>15</sup> Pasqual Maragall is a well known Catalan politician who has been diagnosed with Alzheimer's disease and has created a research foundation <http://www.alzheimerinternacional.org/>

<sup>16</sup> <http://www.alzheimerinternacional2011.org/>

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raise (private) funds, exchange ideas, and contribute towards the European initiative on Alzheimer's disease.

## Italy

In Italy, the Ministry of Health, the Ministry of Labour and the Ministry of Research promote research on Alzheimer's disease and other types of dementia by financing universities and clinical research institutes. In 2002 the Ministry of Health founded the Alzheimer Commission<sup>17</sup> which aims to promote and improve health and the quality of life of people suffering from Alzheimer's disease. It also acts as a research and advisory body with a particular focus on the coordination and guidance of the regions to establish and implement measures to improve social conditions, and the health of people with Alzheimer's disease and their families.

## Norway

Norway has a national dementia plan called "Dementia plan 2015"<sup>18</sup> which is a subplan of the Care Plan 2015. The Dementia plan has a number of strands including improving care for people with dementia and a four year action programme of research (2006-2010) in association with the Research Council of Norway. The research programme focuses on research into the organisation and delivery of municipal health and care services including: the use of individual care plans, designing and staffing home care services and the use of technology to assist people with cognitive impairment.

## Czech Republic

In September 2010, the Czech Republic announced the creation of a national plan on Alzheimer's disease. This plan will be put together between now and June 2011 by the Ministry of Health working with the Ministry of Labour and Social Affairs, the Ministry of Finance and the Ministry of Justice.

## Dementia Research: the EU Response

The main mechanism for the EU to fund or support dementia research is through the research framework programmes. However, dementia and particularly Alzheimer's disease were given a boost in 2008 as a key priority of the French Presidency of the EU. This has led to Alzheimer's disease and dementia rising up the EU agenda culminating in an agreement for a European initiative on Alzheimer's disease and other dementias, which is currently in development.

The 2010 Belgian Presidency of the EU also made dementia a priority with the organisation of a high level meeting on dementia held on 26-27th November 2010<sup>19</sup>. The sub-themes of the conference were structural initiatives at EU, national and local level, stigmatisation of dementia and adapting dementia care.

## EU policy

In October 2007, the European Commission published the EU **Health Strategy**, a white

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<sup>17</sup> <http://www.salute.gov.it/dettaglio/pdPrimoPiano.jsp?id=88&sub=4&lang=it> (in Italian)

<sup>18</sup> <http://www.regjeringen.no/upload/HOD/Dokumenter%20KTA/DementiaPlan2015.pdf>

<sup>19</sup> <http://www.health.belgium.be/eportal/Aboutus/eutrio/health/Dementia/index.htm?fodnlang=en>

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paper (COM 2007-630) entitled “*Together for Health: A Strategic Approach for the EU 2008-2013*” laying out the direction of EU health policy from 2008 to 2013. The EU Health Strategy mentions dementia in the context of developing a “better understanding of neurodegenerative diseases such as Alzheimer’s”. In addition, the accompanying Commission working document (European Commission, 2007) mentions dementia in the context of tackling age related neurodegenerative diseases and the possibility of future EU-coordinated initiatives on specific diseases that may include dementia and Alzheimer’s disease.

The June 2008 European conference on mental health and well-being organised by the Slovenian Presidency of the EU developed a “*European Pact on Mental Health and Well-being*”<sup>20</sup>, which included mental health in older people as one of its four priority themes.

The French Presidency of the EU organised a conference on “The fight against Alzheimer’s and related disorders” on 30-31 October 2008 in Paris. This conference paved the way for the **Council Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing, in particular Alzheimer’s disease** (December 2008). These conclusions called on the Commission to adopt an initiative on neurodegenerative diseases around four main themes of research, exchange of best practices for prevention, early diagnosis, care and treatment, improvement of epidemiological data and exchange of best practices on the rights of dementia patients. The Conclusions also stated that neurodegenerative disorders were an area where a joint programming approach could bring added value.

The Commission then went on to adopt a **Communication on a European initiative on Alzheimer’s disease and other dementias** (COM 2009/379 of 22 July 2009), which outlined the case for EU action and identifies a number of key areas:

- Prevention and early diagnosis:
  - Promoting good physical and mental health;
  - Further research into “healthy brain” lifestyles.
- Shared European effort to better understand dementia including epidemiological knowledge and coordination of research:
  - Implementing conclusions of EuroCoDe project;
  - Use European health examination survey to provide European-wide data on dementia prevalence;
  - Council recommendation on joint programming initiative on neurodegenerative diseases.
- Sharing of best practice in caring for people with dementia using the Open Method of Coordination.
- Establishing a European Network on the rights of people with dementia.

Also on 22 July 2009, the Commission published a **proposal for a Council Recommendation on measures to combat neurodegenerative diseases, in particularly Alzheimer’s disease** which proposed:

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<sup>20</sup> [http://ec.europa.eu/health/archive/ph\\_determinants/life\\_style/mental/docs/pact\\_en.pdf](http://ec.europa.eu/health/archive/ph_determinants/life_style/mental/docs/pact_en.pdf)



- National action plans on Alzheimer’s disease and related diseases;
- A strategic research agenda on neurodegenerative diseases;
- The undertaking of a pilot project of the Joint Programming approach by the Commission.

The Commission is now working on a **European pilot initiative for combatting neurodegenerative diseases in particular Alzheimer’s disease**, under the “Joint Programming” approach which will entail:

- The definition, development and implementation of a common strategic research agenda;
- Large scale studies to assess the effectiveness of existing treatments;
- Large cross-border population studies to address risk factors;
- Establishment of databases and registries;
- Standardisation of diagnostic criteria and assessment tools throughout the EU.

The European Parliament has long been supportive of European efforts in the area of dementia and its committee on the Environment, Public Health and Food Safety is currently drafting a report on the European initiative on Alzheimer’s and other dementias. Portuguese MEP Marisa Matias, is preparing the report which was successfully adopted by the Committee and was adopted by the European Parliament in plenary in January 2011.

## EU research framework programme

The Research Framework Programme is the EU’s primary tool for funding research and one of its key thematic areas is health. Both the 6th (FP6) and 7th (FP7) research framework programmes have supported research into dementia, in particular, Alzheimer’s disease.

The current programme, FP7 (2007-2013) allocates €6 billion (out of a total of €50 billion) for health funding and went further than FP6 in having a designated sub-theme on “Research on the brain and related diseases, human development and ageing” of which a third of funding was allocated to neurodegenerative disease research. To date, FP7 has funded 16 projects to the tune of €82m in the area of neurodegeneration<sup>21</sup>, which have investigated areas including biomarkers and probes, underlying mechanisms and therapy for memory loss, and restorative approaches for therapy of neurodegenerative diseases.

Neurodegeneration-related projects have also been funded under other cooperation FP7 themes. For example, there was an ICT theme project looking at the social, ethical and privacy issues of ICT and ageing and under the knowledge based bio-economy theme LIPIDIET, a project on the therapeutic and preventative impact of nutritional lipids on neuronal and cognitive performance in aging, Alzheimer’s disease and vascular dementia under the knowledge based bio-economy theme.

FP6 (2002-2006) funded 18 projects related to neurodegeneration with funding totalling €83.5m<sup>22</sup>. Projects covered a wide range of areas including early disease markers and animal models. In addition, there was an ERA-NET project launched during FP6 called ERA-

<sup>21</sup> For a full list of relevant FP7 projects, please see annex two.

<sup>22</sup> For a full list of relevant FP6 project, please see annex three.

NEURON<sup>23</sup> aimed at creating a strategic group of research funding organisations to facilitate coordination and implementation of research into brain diseases.

The eighth research framework programme (FP8), which is expected to run from 2014-2020, is currently in preparation. The European Commissioner for Research Máire Geoghegan-Quinn has already announced her intention to simplify procedures for FP8 and there is discussion of a focus on five “grand themes”, one of which will be health.

## Innovative medicines initiative

The Joint Technology Initiative on Innovative Medicine<sup>24</sup> (IMI - Innovative Medicines Initiative) is a pan-EU public-private partnership between the pharmaceutical industry represented by the industry association EFPIA<sup>25</sup> and the European Commission, which grew out of the FP6 project “European Technology Platform on Innovative Medicines” (InnoMed).

The key aims of the IMI are:

- To support faster discovery and development of innovative medicines for patients;
- To enhance Europe’s competitiveness by ensuring a dynamic high technology bio-pharmaceutical sector.

The initial IMI strategic research agenda refers to dementia in the form of Alzheimer’s disease noting that “a clear need for disease modifying agents that could stop or slow the progression of Alzheimer’s disease” and for “more effective symptomatic treatments”. Following its first call for projects in 2008, IMI funded Pharmacog<sup>26</sup>, a project on the “prediction of cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development”. No dementia related projects were funded under the 2nd call for projects in 2009, and it is unlikely there will be any projects under the 3rd call for projects (2010 - ongoing) as the priority areas identified are not dementia related.

## Public health programme

The second programme of community action in public health (“public health programme”), which runs from 2008-2013 is the primary tool used by DG SANCO to encourage and fund public health research. The funds available to the programme are €321,500,000. The programme does not specifically mention dementia, but it does make several references to the health related challenges of ageing including:

- The challenge of an ageing population;
- The need to address ageing related health issues.

The previous public health programme (2003-2008) funded a health information project managed by Alzheimer Europe called “EuroCoDe<sup>27</sup>” whose aim was to develop European dementia related indicators.

In 2010, the public health programme part-funded a project to examine current epidemiological studies, agree on common definitions for diagnosing dementia and assess

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<sup>23</sup> For details of ERA-NEURON projects, please see annex three.

<sup>24</sup> <http://www.imi-europe.org/>

<sup>25</sup> [www.efpia.org](http://www.efpia.org)

<sup>26</sup> [http://www.imi.europa.eu/sites/default/files/uploads/documents/projects/imi-1st-call-factsheets-pharma-cog\\_en.pdf](http://www.imi.europa.eu/sites/default/files/uploads/documents/projects/imi-1st-call-factsheets-pharma-cog_en.pdf)

<sup>27</sup> [http://ec.europa.eu/health/ph\\_projects/2005/action1/action1\\_2005\\_10\\_en.htm](http://ec.europa.eu/health/ph_projects/2005/action1/action1_2005_10_en.htm)

existing practices within dementia care models. The project is being led by the French National Authority for Health.

## Other EU initiatives/programmes

The EU funded Marie Curie programme<sup>28</sup>, which gives grants to researchers, facilitates training networks and schemes to promote exchanges between academia and industry, has funded initiatives related to neurodegenerative diseases including a PhD training programme on the early pathomechanisms of AD and a training network in the area of Alpha-Synuclein-related Brain Diseases.

The DG INFOSOC Ambient Assisted Living programme<sup>29</sup>, which is co-funded by the European Commission, Member States and partner organisations, aims to improve the quality of life of older people and to strengthen the industrial base in Europe through the use of Information and Communication Technologies (ICT). The programme published a call for proposals on demographic ageing and eight projects related to dementia or Alzheimer's were funded to a total of €15.5m<sup>30</sup>.

COST<sup>31</sup>, a European intergovernmental network on cooperation in science and technology, which is funded by FP7, has also played a role in neurodegenerative diseases for example through the NEREPLAS and NEURINFNET projects. They look at neuronal processes underlying functional recovery and neuroinflammatory and neurodegenerative processes as they occur in multiple sclerosis and Alzheimer's disease, respectively.

The European Strategy Forum on Research Infrastructures (ESFRI)<sup>32</sup> is the main EU initiative designed to facilitate the coordination of infrastructure relevant to neurodegenerative disease. ESFRI was established in 2002 when Member States and the Commission recognised the need to develop a common policy for access to and the provision of new and improved research infrastructures<sup>33</sup>. Funding for construction of facilities comes from Member States.

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<sup>28</sup> [http://ec.europa.eu/research/fp6/mariecurie-actions/action/action\\_en.html](http://ec.europa.eu/research/fp6/mariecurie-actions/action/action_en.html)

<sup>29</sup> <http://www.aal-europe.eu>

<sup>30</sup> For details of AAL projects, please see annex four.

<sup>31</sup> <http://www.cost.esf.org>

<sup>32</sup> [http://ec.europa.eu/research/infrastructures/index\\_en.cfm?pg=esfri](http://ec.europa.eu/research/infrastructures/index_en.cfm?pg=esfri)

<sup>33</sup> For details of ESFRI projects, please see annex five.

# Part 2 – The Dementia Research Working Group Meeting

## Overview of Presentations

### Introduction

Chris Davies, Liberal Democrat MEP for the North West of England and member of the Parliament's Environment, public health and food safety committee, opened the meeting welcoming all participants. Mr Davies then handed over to Baroness Sally Greengross, independent member of the House of Lords and Chief Executive of ILC-UK.

Baroness Greengross compared the challenge of dementia to climate change in magnitude. She thanked Chris Davies MEP for kindly agreeing to host the meeting and Sarah De Block in Chris Davies' office for her organisational efforts. Pfizer was also thanked for sponsoring the event and Baroness Greengross highlighted the productive working relationship the ILC-UK had enjoyed with Pfizer on numerous occasions.

Looking back to ILC-UK meetings on dementia research in the House of Lords in June 2009 and the UK Ministerial Summit on Dementia Research held in the same year, Baroness Greengross said there was growing evidence that both the current and previous government recognise the importance of dementia research. However, one country alone, Baroness Greengross stressed, cannot move forward on this issue, as it is a European as well as global issue.

Baroness Greengross explained that the International Longevity Centre-UK is one of an alliance of 12 global ILCs. The alliance has already held several international meetings on the subject of dementia, most recently in South Africa. All the ILCs now consider dementia as a significant global challenge and a priority.

The ILCs look not only at dementia, but at issues of longevity and the effect of demographic change on society. Assuming a lifecourse and multidisciplinary approach, as think-tanks, the ILCs are not campaigning organisations for older people, but seek to help develop ideas and policies for the future.

Since the Ministerial Dementia Research Summit in 2009, which was organised by the Department of Health and the Medical Research Council, the ILC-UK produced a report, which served as an effective call to action. The summit in the UK served as a catalyst and many Member States such as France, have similarly responded with national plans and high level leadership to drive the dementia research agenda forward.

To conclude, Baroness Greengross stressed that all governments as well as EU and international institutions need to prioritise dementia within current health, social and research policy. Baroness Greengross urged everyone to work together to find common solutions, and stressed that this issue is not only critical for this generation but for the next, affecting both old and young.

### **Jean Georges, Executive Director of Alzheimer Europe, Overview of EU landscape and dementia**

Jean Georges thanked Baroness Greengross and said he was pleased to be asked to speak

at the meeting. He said he was going to deviate slightly from the brief, as this was a rather ambitious project for a ten minute presentation, and instead focus on some of the recent work Alzheimer Europe had been involved with.

Alzheimer Europe has members in 30 European countries including non EU countries like Norway, Switzerland and Turkey. Alzheimer Europe coordinated the EU funded EuroCoDe project which looked at the prevalence of dementia in Europe, which had not been updated since the EuroDem project in the late 1990s. The project had set strict criteria and found 17 studies that met the criteria. EuroCoDe showed results consistent with EuroDem for the prevalence of dementia in men, but revealed a significantly higher risk of dementia in women than EuroDem. Women over 95 have a one-in-two chance of developing dementia. In total around 7.3 million people are affected in the EU and this number is expected to double or treble by 2050. This figure refers only to patients, so it is important to also remember the carers, who are usually partners or spouses, children or grandchildren. The last European Commissioner for Health Androulla Vassiliou talked about 19 million people affected once carers are taken into account.

EuroCoDe also looked at cost of dementia in 2008 and estimated that it was around €160 billion of which 56% were the costs of informal care.

He also stressed the need to improve early diagnosis. In a study asking carers about the time period between them first noticing problems and receiving a diagnosis, huge differences were found, for example 10 months in Germany and 32 months in the UK. Even 10 months is a significant time he noted, if you are worried about your own health or that of your partner/parent.

Another key issue is the impact of dementia on carers. Next year is the European year of healthy ageing, which must specifically address the needs of carers as being a carer has an impact on health. A study of 1000 carers in Europe asking about time spent looking after dementia patients revealed that even in the early stages of dementia, 20% of informal carers spent over 10 hours a day caring. The study did not specify what was meant by caring, so in some cases that could mean having to be just physically present with the individual. By late stage dementia, 50% of carers spent more than 10 hours a day caring. The same survey looked at the availability of support services for carers and asked carers if they were aware of the services. Respite care is very important for carers, but overall only 33% of carers knew that it was available. There were big differences between countries, for example 3% of carers in Spain were aware of respite care, compared to 51% in Scotland.

Alzheimer Europe also looked at patient information including whether patients are made aware that they have been diagnosed with dementia. According to their carer, 60% of people knew about their diagnosis. However, once again, there were differences between countries, for example, 23% of patients in Spain were aware of their diagnosis compared to 80% in Scotland. The reasons for this are unclear and could relate to the stage of diagnosis i.e. a patient diagnosed in a late stage of dementia may not be able to understand the diagnosis even if they are informed.

The Alzheimer Europe Paris Declaration in 2006 called for dementia to be recognised as a European priority for public health and for better collaboration and more funding. He said he was pleased that by 2010 a number of countries had recognised dementia as a public health priority and developed dementia strategies like England, France and Norway. The European Commission has also become involved and the European Parliament should be thanked for its work to push dementia up the agenda.

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**Pieter Jelle Visser, Alzheimer Centre, Department of Psychiatry,  
School for Mental Health and Neuroscience, University of Maastricht -  
Alzheimer research funding on the European level, the Joint Programming  
Initiative on Neurodegeneration**

Dr Visser explained that he is actively involved in research on the early diagnosis and treatment of dementia including the Joint Programming Initiative on neurodegeneration. The idea behind the Joint Programming Initiative is that there are topics of major social challenge, which affect all and could benefit from a European approach. Currently 85% of funding related to dementia is spent on the national level. European cooperation between these nationally funded research programmes should prevent fragmentation, increase collaboration amongst countries, help to harmonise national strategic research approaches, improve synergies and increase accountability.

Alzheimer's was one of the first topics to be chosen, although in fact collaborative activities at the European level began before the Joint Programming Initiative as a result of Nicolas Sarkozy's efforts to make Alzheimer's disease a European priority. Research spending in the EU shows limited funding and high fragmentation for dementia research including many EU level initiatives.

The three main players are the European Commission, the Member States and industry and there are a number of permutations including:

- The Commission's research framework programme
- The Member State/Commission collaboration that is ERANET
- Article 169 collaboration between Member States and industry
- The European Social Fund and the Structural Funds
- The European Strategy Forum on Research Infrastructures (ESFRI)

The Joint Programming Initiative on neurodegeneration (JPND) is designed to align national and European neurodegeneration programmes and to initiate new collaborative projects. Projects will be started in basic, clinical and health care research.

JPND ([www.neurodegenerationresearch.eu](http://www.neurodegenerationresearch.eu)) started in January 2009. The European Commission has given funding for organisational support via JUMPAHEAD, but not for the actual research. There are 24 Member States involved. The aim is to develop a strategic research agenda, create better mechanisms and channel funding to build the agenda, and then to have a la carte programme on specific topics including calls for collaborative research projects from different countries. It is a bit complex, but it is where things have to start.

Member States are the highest authority on the JPND and each Member State can appoint two members to sit on the management board. There is also a scientific advisory board (SAB) to come up with research topics. The Management Board reports to the European Commission.

The first task is to map research efforts and needs. The SAB develops research priorities and the Management Board decides how to implement those priorities using existing European instruments, launching new joint calls, or increase collaboration between ongoing national initiatives such as are underway in France, Sweden and the UK. There is already a joint UK and German initiative underway.

The Scientific Advisory Board has already developed priorities and a 2011 pilot call on CSF

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biomarkers will be undertaken. There will also be workshops on the strategic research agenda in 2011 and pilot projects should start in 2012. In 2013 it is already foreseen that there will be two to three other projects.

## **Florence Lustman, Chief Co-ordinator of the French Alzheimer's Plan – Implementing a comprehensive dementia strategy: lessons from the French Alzheimer's plan, how to integrate research into national action plans**

Ms Lustman began with a core message, which was that the key to national action plans is cooperation between different sectors of public policy. France is currently on its 3rd Alzheimer's plan. The first point to be made in this area is that Alzheimer's is a disease, but is in fact much more than a disease, as it is a problem for society as a whole. At the end of the first two national plans which were mainly "health oriented", it was stated that there was still a lot more to do to improve the quality of life of patients and carers.

The first objective of the current plan, which is rather optimistic Ms Lustman stressed, is to cure Alzheimer's disease by developing a medical treatment through in-depth knowledge of the condition. Research is at the heart of the national plan 2008-2012. However Professor Joel Menard and other senior figures in France knew that despite a huge effort on research, no treatment was likely to be available by 2012. There was a lot to be done in parallel to take care of patients and carers, which is the 2nd objective of the plan. The 3rd objective is one of respect and dignity for people with dementia.

The ultimate aim of the plan is a personal pathway for a person with dementia starting with diagnosis (early diagnosis being very important) until the end of life, whether this is at home or in a hospital or nursing home. A number of practical solutions have been developed to improve the quality of life of patients and families at each step of the pathway.

Research is still needed into diagnosis, as definitive diagnosis is currently only available with a post mortem. Further research in the social sciences is also required in order to validate non-pharmaceutical approaches. Ms Lustman expressed the opinion that the pharmaceutical treatments that are currently available do not work for all patients and even when they do work, they typically only offer a better quality of life for some patients for a matter of months, but do not respond to real needs. In France the calls for projects in the social sciences did not result in many proposals, sometimes none at all, therefore funding is not everything, if the interest from the research community is not there. Ideally it would be possible to attract teams working in other fields to move into Alzheimer's research. Right now there is a chance that various non-pharmaceutical treatments may have some effect, but without relevant research, this cannot be confirmed. Research also requires research ethics and ethical reflection. For example, there are ethical considerations in relation to encouraging patients to enter clinical trials and obtaining consent.

The French research strategy identified objectives include:

- Reinforcing strengths in Alzheimer's research: including facilitating the work of the best established multi-disciplinary centres, exploiting the cohorts already established, and setting up a nationwide genomic study. It was also felt necessary to attract new teams in cellular and vascular biology and have set up a centre for biological and sociological research. There is now a network of 400 memory clinics, which allows diagnosis in less than 50 days, and information they collect is being standardised, so that it can be used for research purposes.

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In the middle of the 2008-2012 plan, it can already be acknowledged that some parts of the plan take a lot of time to introduce or initiate e.g. launching calls and gathering new teams, both of which need a lot of prerequisites.

- Increasing collaboration with pharmaceutical and biotech companies and attracting research funding from them. It has been possible to attract private company funding for the Alzheimer's research foundation, which will allow the research part of the plan to continue even after 2012. It would be a waste of time and money to stop everything at the end of five years as far as research is concerned.

### **Michael Ryan, Clinical Lead, Alzheimer's Active Immunotherapy Development Programme, Pfizer – The challenges of Alzheimer's disease research**

Dr Michael Ryan introduced himself as leading a clinical research team working on a vaccine for the treatment of Alzheimer's disease. The use of an iceberg as a metaphor is very apt, as he said it only really possible to see the tip of the problem. He said that clinicians can now diagnose most forms of dementia syndrome fairly easily, including early Alzheimer's disease, but detecting presymptomatic Alzheimer's disease is much more difficult, even with known risk factors including genetic susceptibility.

Alzheimer's Disease International has quantified the worldwide cost of dementia to be at \$604 billion and if dementia care were a country, it would be the world's 18th largest economy. Given the large burden of Alzheimer's disease and other dementias, it is easy to see why there is an interest and imperative for researching in this field.

There is, though, some hope in the development of new potential treatments, which mainly focus on toxic amyloid beta and tau including a number of drug candidates for the former and some for the latter. Everyone understands the opportunity and the need, and projects are underway to expand the development of candidate drugs.

There are, however, a number of research challenges relating to complexity, resources and time. Complexity refers to the need to better understand some of the underlying disease biology including genetic susceptibility and inflammation. Most therapies currently in development target one piece of the biology and this may not be enough to slow down the disease, so multiple pathways may need to be targeted. Alzheimer's disease patients often have comorbidities including heart disease, which means it can be difficult to tell whether a drug candidate is causing adverse effects or they are due to other pre-existing medical conditions. Measuring clinical change over time in a slowly progressive disease can be difficult and early changes related to Alzheimer's disease might be too small to be picked up.

Resources are also a problem as AD clinical trials are becoming more demanding and often require MRIs, PET scans and lumbar punctures. Increasing technical complexity means research is more expensive and fewer research sites may be able to offer the full array of research technologies. As such, there are a finite number of research centres that are capable and motivated to carry out this important clinical research. At times it seems that there is an incredible mismatch between the global Alzheimer's disease burden of care and the number of people interested in basic and clinical research aimed at this disease. He said that research sponsors are finding bottle necks in research centres, including a lack of skilled clinicians. It can cost \$750m or more to develop a drug candidate and the failure rate can approach 90%. This does create concerns for the research budgets of many sponsors.

Time is also an issue. Due to the complexity of the research, it can take more than ten years

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from drug discovery to regulatory approval, leaving only a few years for the drug to be on the market until patent expiry.

What are the solutions? The key is collaboration between all interested parties; clinicians, patients, pharmaceutical industry, academia. Some of the strongest collaborators are in Europe. It is not always easy to understand what payers expect and what they will fund. Regulatory approval and funders must collaborate to assure that expectations are clear.

The EU model is good and there is also some collaboration between Japan and the USA. We also have to think about risk sharing via non traditional alliances. Perhaps development costs could be shared to spread the risk while maintaining a high level of interest in the research.

### **Alistair Burns, Clinical Director of Dementia at the Department of Health – What are the top priorities for new research and lessons from the UK experience**

Professor Burns began by saying thanks to Professor Sube Banajee (present) for his work on the National Dementia Strategy. Research was a key aim of the strategy and led to the Department of Health and Medical Council Ministerial Research Summit in July 2009, a report of which was published by ILC-UK in November 2009.

The summit and the report focused on three aspects: priorities, barriers and solutions. This was largely based on the Alzheimer’s Society’s idea of “cause, cure and care”, but prevention was also mentioned. The UK is very active on research, but when it comes to clinical trials, 12-15% of cancer patients in the UK are involved in trials, compared to less than 0.5% of dementia patients.

He explained that he was pleased the dementia research strategy group set up from the Ministerial Research Summit has survived this year’s general election and the subsequent change of government. In fact, there are good indications that the new coalition Government may even accelerate activities. The new care minister Paul Burstow has been interested in the area of dementia for years and dementia was mentioned as a priority in the coalition Government agreement.

The dementia research strategy group identified five areas of importance: prioritisation, awareness, increasing access, better ways of working, and translation of work into practice. Specific points raised include the need for longitudinal studies, prevention (along the lines of the Alzheimer’s Society’s “What’s good for your heart is good for your head” campaign). He said it would be incredibly beneficial if some of the energy put into prevention of stroke and myocardial infarction could be directed towards dementia.

Professor Burns then went on to explain that behaviour problems associated with dementia are in the psychosocial field (drugs are not), and sometimes there is a tension between drugs and the psychosocial approach; it would be great to combine these two strands.

The vast majority of care homes are outside the NHS system, so there is an issue about paying for care and funding research. A third of people with dementia are in care homes.

Professor Burns said the strategy group was discussing the creation of a register for researchers/organisations with an interest in dementia in order to increase access to research. Funding is important as for every £1.30 spent on cancer, only 5 pence is spent on dementia (Alzheimer’s Research Trust, 2010)<sup>34</sup>, but it is not only a question of funding, but also the organisation of research.

There needs to be better ways of working, integrating clinical priorities into the research agenda is essential and this must include links with industry. Finally, translation of research is important. It can currently take 20 years, but we must decrease this. The translation group is looking at areas where we can realise changes immediately. These areas include: early diagnosis, care in hospitals, care in care homes, reducing anti-psychotic drugs, and looking after and supporting carers at home.

Lessons that can be learnt from the UK include the importance of Ministerial buy-in. We also need to encourage people to be involved in research including young researchers and people from other fields. Finally the UK greatly values its links with Europe and is working on a number of joint projects.

## Discussion and Key Themes

This section will provide an overview of some of the key themes that emerged from the open discussions following the presentations.

### Research Priorities

With regard to research priorities the lack of up to date epidemiological research was highlighted as a priority as this makes it difficult to measure the diagnostic delay. A systematic review found that epidemiological research peaked in the 1990s in high income countries, and since then there is a distinct paucity of data on the prevalence and incidence of dementia.

The incidence of some dementia syndromes for example vascular dementia could be declining it was suggested due to public health campaigns on the prevention of Cardiovascular disease, but without up to date research, it is hard to form any concrete conclusions. We also do not know whether people are accessing services earlier. Information on costs is also highly provisional as most of the data was collected in the 1990s and countries are no longer collecting. For example, the healthy ageing study SHARE excludes people with dementia as they are too cognitively impaired to participate.

One delegate drew attention to the European Alzheimer's Disease network which is a 14 country collaboration. It was suggested the network would be happy to collaborate further. Another point in relation to priorities was that although cure and care are important, physiological research should not be neglected as currently we do not know enough about early stage Alzheimer's disease for diagnosis and treatment. There is a lot of animal research, but it does not translate easily in human studies, so more population based high tech studies measuring biomarkers are needed.

The importance of collaboration across Europe was endorsed by many delegates. Data on care and discrimination was also highlighted as a priority, as was empirically based sociological research. It was necessary to think of cost effectiveness and prevention of harm. In public health terms, chronic illnesses are now a great concern and dementia is the most expensive. Standard and Poors looked at developed economies in a recent report and found the proportion of long term care taken up by dementia can be anything from 40-80%. Standard and Poors argue that developed countries have around four to six years to come up with the solution to long term care and dementia care or it will cripple our economies. It is therefore imperative that governments address this impending crisis now through effective policy interventions. There

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<sup>34</sup> For further information on the cost of dementia, see <http://www.dementia2010.org/reports/Dementia2010ExecSummary.pdf>

is emerging evidence to suggest effective early interventions such as early diagnosis coupled with responsive services yield both social and fiscal benefits. Evidently such interventions rely on state funding for health and social care and in low to middle income countries, governments are generally resource poor when it comes to prioritising dementia over for example certain communicable disease. The WHO is currently working on a mental health global gap plan for resource poor countries.

The wider question of research funding was also raised by many delegates, in the UK it was noted that while there may be exceptions, generally there is significant competition to secure research funding from charitable trusts. The suggestion of low take up for certain funding streams in the UK it was argued was not necessarily linked to low levels of interest by the research community, but rather complicated application criteria.

## **Clinical Trials**

The issue of clinical trials participation was also raised and concern was expressed with regard to the low number of patients who enroll in clinical research studies. In the UK, less than 1% of dementia patients are involved in trials of experimental therapies. Some of the participants at the meeting felt that it would be necessary to test these experimental therapies in patients with milder forms of the disease so that they could target amyloid reduction before plaques appear in the brain. One theory proffered is that amyloid exerts an upstream “domino effect” on downstream pathways that actually cause neurodegeneration and clinical symptoms. So to move forward there needs to be a better clinical trials infrastructure that is capable of attracting a pool of patients in the very early stages of the disease process. One delegate also explained that some of the best clinical research centres argue that clinical trial protocols are often too demanding. Thus one of the solutions would be to initiate processes to identify larger cohorts of potential research subjects because the proportion of eligible patients is relatively low.

In France, the results from several surveys showed that patients are not only supportive of dementia research, but wanted to participate in clinical trials. Clinical trial participation was shown to be beneficial in not only helping the individual to come to terms with the condition, but provided them with hope for the future that a cure may one day be found.

## **Diagnosis rates and the discrepancy across EU Member States**

There was considerable discussion with regard to the disparity in diagnosis rates across the Member States, for example why the UK had such a poor rate of diagnosis compared to Germany. Two thirds of people in the UK do not receive a diagnosis, which is why it has been highlighted as a priority in the National Dementia Strategy. The point was also raised that there are significant discrepancies if geographic areas are considered, particularly with regard to urban and rural environments; a link can be made between diagnosis and the provision of primary care services. The differences though could also be clinical, in relation to the availability of memory clinics. Indeed a range of factors need to be considered, including as one delegate highlighted, the stigma and discrimination associated with dementia across different countries. This was one of the central themes of the recent Belgian Presidency Conference on dementia.

## **The role of GPs and diagnosis rates**

The role of the GP is also very different across Europe. For example, in Germany a GP can diagnose and treat Alzheimer’s disease, but in other countries the patient needs to be referred to a specialist for diagnosis and there may be a waiting list. In UK it was mentioned that there is a high proportion of geriatric specialists, but they do not work as closely with GPs, as perhaps

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they should. It was explained that France has a network of 400 memory clinics and neurologists that can diagnose dementia, but there have been difficulties in GPs making referrals as they cannot make the diagnosis themselves. Some GPs may also not view dementia as a treatable disease or realise the range of treatment and support options available. In addition, GPs are not aware that patients can specify how they want to be treated.

In public opinion surveys in France, 91% of people said they would like to be informed of a diagnosis of dementia, but some GPs do not recognise such surveys and instead may feel they should decide what is in the best interests of the patient. The attitude, behaviour and knowledge of GPs with regard to dementia were considered by many delegates to be a cross-cutting issue for most Member States. The point was also raised that it is not simply a case of making a good clinical diagnosis, but rather communicating this to the patients and families in an understanding and sympathetic manner. This is also important for the immediate provision of care and treatment. It was also noted that it was not simply a case of educating and raising awareness amongst GPs, but to reach out to all health care professionals, for example in Sweden there are some dementia nurses in primary care.

### **Hospitals and dementia care**

The substandard treatment some individuals with dementia receive in hospital was also highlighted as an area of significant concern by several delegates and can be borne out in the longer average length of their stay compared to similar individuals who do not have dementia. The need to educate health professionals and have dedicated dementia wards were raised as potential solutions to this problem. Referring to hospital admissions in the UK, 40% of people with dementia admitted to hospital with another medical problem would not need to be admitted if they did not have dementia. Good dementia care can cut hospital stays from three to five days according to one research study in the UK, thus demonstrating that hospitals are not necessarily the best place for dementia patients and constitute a significant inefficiency in the health system. This could be avoided by addressing the issues of dementia patients more specifically. One neurologist present said he had to do further training to become a geriatrician in order to be able to treat dementia patients. In addition, he had been required to discuss diagnosis with a representative of the patient in the community.

### **Anti-psychotic drugs**

Another area of concern was the overuse of anti-psychotic drugs particularly in residential and care home environments. Research demonstrates that people with dementia are particularly sensitive to the effects of anti-psychotic drugs and that they result in an increased mortality rate amongst dementia patients of around 1%. In the UK one of the concerns is that these drugs are more commonly used than is appropriate or necessary. It is possible that up to a third of people with dementia are prescribed them, which could mean 1800 additional deaths in England each year. This would be a much larger number across Europe as a whole.

In France it was reported that 17% of people with Alzheimer's disease have been prescribed anti-psychotic drugs, despite the fact that this is nearly always contraindicated. GPs and specialists it was suggested, make these prescriptions because they cannot manage the behaviour of the patient. Care staff in nursing homes in France where 27% of patients receive prescriptions, are not trained how to manage dementia patients. This over reliance on pharmacological interventions in the form of anti-psychotic drugs is symptomatic of the limited treatment options available and a low level of understanding of non-pharmacological interventions. One delegate who had worked as a psychiatrist in both Spain and England, also

mentioned the problem of off-licence use of drugs for dementia patients, noting that in England stopping off-label prescription took longer than in Spain, where changes were immediate.

## **Human Rights and Discrimination**

The rights agenda for people with dementia was another area of concern for several delegates. Issues raised included people with dementia lacking mental capacity particularly in the middle to latter stages of the disease progression and how as a society we safeguard and protect the rights of individuals with dementia. One delegate said that she would like to see a group of lawyers undertake research into a rights based approach, to explore the type and form of discriminatory approaches, and how these could be considered violations of human rights.

It was suggested that the European Commission should make a yearly report on a rights based approach for people with dementia. It was also noted that there were some difficulties with the EU Agency for Fundamental Rights to recognise age discrimination, which has a link to dementia. The UN is also working on a possible convention on the rights of older people and the AGE Platform had a project on the fundamental rights of people in need of care and long term assistance. In the UK the Equality and Human Rights Commission are undertaking a formal inquiry on the human rights of older people in need of care in the community.

One delegate also raised the question of how to involve people with dementia and their carers in decision-making at the micro and macro level, so not just about the care they receive, but the funding structure and their elected representatives behind the decisions. The Aarhus convention was raised as a possible mechanism, which would grant certain NGOs the right to raise issues on behalf of people with dementia.

## **The role of carers**

The fundamental role of carers was also raised by several delegates. As unpaid carers form the bedrock of support and care across Europe, their inclusion on the research agenda should not be overlooked. It was argued that there are many opportunities to prevent negative consequences for carers as some research clearly demonstrates, but they are not always realised or taken up. One area of considerable concern was the physical and health problems associated with caring. Research suggests carers suffer mental health problems in particular, depression, as a result of their caring responsibilities. It was also argued the European year against poverty and social exclusion should consider the experience of carers in relation to stigma, isolation and discrimination by association and thirdly, poverty prevention for carers is important due to the opportunity costs of informal care. There are a range of actions, initiatives and reforms which are needed across Member States including: welfare for older carers and enabling younger carers to reconcile care with employment.

## **Recruitment, training and capacity**

A range of skills shortages were identified in the dementia research arena. It was suggested high tech research needed skilled researchers and many people with the necessary skills are currently working in stressed health care systems that do not leave them with any time for clinical research. Simply allowing people to dedicate time to clinical research would be an improvement.

Recruitment in the UK it was suggested was not sufficiently linked with care pathways. Trial recruitment was a parallel and separate process. Currently, disease registers and memory clinics are being looked at in the UK to see if this could help improve interconnectedness. It was also noted that economists and sociologists need to be encouraged into dementia

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research. The need for more neuropathologists was also highlighted by several delegates as a priority, particularly the need for increased funding to facilitate a greater take up.

## **Migration and Immigration**

Another issue highlighted referred to the number of people with dementia not living in their country of origin. For example, in Luxembourg, one third of people are not native Luxembourgers, but many are staying there after retirement having worked in the country for many years. This raises the problem of people with another native language not receiving enough support in care homes in Luxembourg. It was noted that Sweden had incorporated requirements for cultural/ethnic adjustments for example for Finnish and South American residents in Swedish care homes. With an increasingly heterogeneous aging population and culturally diverse workforce, communication in care homes could become a significant area of concern. The question was asked to what extent the affect of migration and immigration had been considered in the context of health and social care provision for people with dementia.

## **Quality of Life**

One delegate noted the need to consider old age more from the perspective of an individual's quality of life. This is particularly pertinent to people with dementia; interventions to delay the onset of the disease should be considered as a priority, so individuals are less likely to reach the later stages of the disease.

## **Awareness, Knowledge and the General Public**

Public awareness of the dementia research agenda was discussed and while in many countries some public polling suggests the general populace is broadly supportive, it was felt further research was needed to assess overall levels of support and understanding. It was argued that if the general populace was educated on the dementia research agenda, particularly on the cost savings of dementia research, the need to find a cure and for more effective treatments to delay the onset or slow the progression of the disease, the public would not only be supportive, but help exert pressure at the national and regional level.

One delegate also noted this cause was not aided by poor reporting by certain national newspapers on dementia research. With headlines proclaiming 'miracle cures', the general public are not only being misinformed, but for the thousands of individuals and families who are struggling with the disease, they are being encouraged to have false hope. It was suggested there needs to be a European clearing house on research results and findings, which is accessible and accurate for the general public.

## **Drivers of the policy and political environment for dementia**

Greater communication with the public was seen by many delegates to be essential. Dementia and dementia research needs to receive the same levels of attention and support as heart disease and cancer in all forms of reporting. The need for more well-known public figures who have personal experience of dementia in their families to come out and discuss the impact it has, would not only help to raise the profile of dementia, but counter negative attitudes of discrimination and stigma. There is also a need for more high level champions at the political and policy level. The European Year of Healthy Ageing could provide a suitable vehicle to promote some of the key messages around dementia. It was also suggested that dementia must be seen in the context of the wider public health agenda and the public health research agenda and the overarching aim should be to turn an undiagnosed and un-helped population into a diagnosed and supported one.



# Conclusions

## Priorities for Basic/Clinical Research

- **Facilitation of fundamental/basic research on Alzheimer's disease.**  
*Greater pre-clinical cooperation between different actors could be a means to further this aim.*
- **Greater research into the impact and how to manage co-morbidities with Alzheimer's disease and other dementia syndromes.**
- **Greater research into rarer dementias.**
- **Increasing the number of neuropathologists in clinical research.**  
*Neuropathology faces immediate service demands, particularly as current experts retire.*
- **Supportive Infrastructure and technologies**  
*The high degree of uncertainty in Alzheimer's disease research, long lead times and difficulty in measuring clinical effects contribute to high attrition rates and high barriers to investment. There needs to be greater public support for this level of investment and risk and a greater understanding of the complementary nature of the relationship between public, charitable and private investment in research.*

## Priorities for Translational Research

- **Improved presymptomatic markers to improve early diagnosis.**  
*Improvements in recognised early stage biomarkers can play an important role in facilitating research and create the potential for earlier and more confident diagnosis.*
- **Clinical Trials**  
*Increasing and speeding up clinical trial enrolment is a priority. This could be facilitated by developing appropriate training, informal networks and incentives for practitioners in primary and secondary care settings, expansion of clinical case registers, clarification of the ethics of clinical trial enrolment and optimising eligibility protocols. Greater consideration should also be given to issues governing consent and mental capacity particularly with regard to the recruitment of individuals likely to be affected by cognitive impairment.*
- **Increase funding and capacity for translational research and more multidisciplinary programmes.**

## Priorities for Co-ordination, Co-operation and Networking

- **Build more co-operative networks across Europe and capacity within research institutions.**  
*Further 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, standardised instruments and the harmonisation of data. The co-ordination of up to date epidemiological data and*

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*increased numbers of longitudinal studies across Europe, was highlighted as a particular priority.*

- **Closer cooperation between industry, regulators and payers to agree clinical priorities and research benchmarks earlier in the process.**
- **Greater links between industry, academia, the public and charity sector.**

*Linkage between clinical research networks including industry researchers and facilities and industry should be actively encouraged. Links between private sector researchers and the public/third sector researchers should also be encouraged.*

- **Creation of a stronger dementia research environment**

*Europe needs to cultivate a research environment which attracts, develops and retains expertise. The dementia research environment needs to reach out to scientists and clinicians earlier in their careers through greater collaborative working with under and post-graduates and GPs through their training. National training centres of excellence should be encouraged to ensure an adequate supply of researchers with the necessary skills and training.*

## **Delivering Health and Social Care**

- **Develop Member State's health service infrastructure to enhance research infrastructure and increase collaborative working between academics, clinicians, researchers, the care industry, patients and their families.**
- **Greater awareness, education and training on dementia and the importance of research across the primary care setting, particularly with regard to general practitioners.**

*GPs remain the main gateway for many individuals and families to receiving a diagnosis. There needs to be greater awareness and understanding of dementia particularly with regard to initial identification of cognitive symptoms, initial assessment, referral to specialists, then continued after care for the individual and patient, as the disease progresses. GPs should also play a more active role in promoting healthy lifestyles to their patients and highlighting the well-known risk factors associated with dementia.*

- **More research commissioned on the disparity of care received by individuals with dementia and without dementia in hospital settings.**

*This should include research on the most effective interventions to support people with dementia in this regard and further consideration of the need for dementia specialist nurses and dementia specialist wards.*

- **Greater integration of care and research to be prioritised at the Member State level.**
- **More carer-centred research.**
- **Greater formal and informal support for carers in the form of welfare benefits, information provision and flexible working.**
- **More research commissioned on non-pharmacological interventions including psychosocial interventions, particularly in residential and nursing care.**





## Equality and Human Rights

- **The rights of individuals with dementia need to be firmly embedded in the human rights agenda.**

*Stakeholders should share best practice across Europe and adopt a human rights based approach to work around dementia in all health and social care settings.*

- **Health and social care providers need to recognise and respond to the increasing diversity of the ageing population with regard to ethnicity, nationality, religion and sexual orientation and integrate an equality based framework into service provision.**

## Raising Political and Public Awareness

- **Explore the level of public support and demonstrate the value of dementia research to a wider audience.**

*The EU should explore public awareness and support for dementia research through a European survey and use the results of the survey to inform discussion on the value of dementia research and highlight common misunderstandings to a wider audience.*

- **Dementia must be viewed as a public health priority and there needs to be greater information on research and clinical developments for the general public.**

*In order to counter misunderstanding and poor quality reporting in the media, and to balance hope with accurate information for individuals with dementia and their families, a comprehensive approach to informing and educating the general public should be adopted.*

- **High level professorial or strategic appointments are needed to push forward this agenda at the national and EU level.**



# ILC-UK Calls to Action

## The ILC-UK calls on the European Commission to:

**Consider a collection of country reports on dementia research funding** - In order to understand the current research funding environment across Europe and help identify gaps in current funding streams.

**Develop a distinct section on dementia research on the official public health portal of the Commission** - In order to counter misunderstanding, frequent poor quality reporting in the press and ensure accessibility and equality of access to information provision across Europe. Research on prevention as part of the public health agenda should also be included.

**Explore level of public support and demonstrate value of dementia research to a wider audience through a targeted Eurobarometer survey** - This would help assess current levels of support and understanding of dementia research and help identify gaps in public information provision.

**Organise an annual conference on dementia research** – This would provide a forum for all actors to come together and share their work and increase cooperation and networking.

**Prioritise dementia research under Framework Programme 8, given the growing burden and financial, health, social and human cost of dementia across Europe.**

**Develop a European Charter to increase the participation of people with dementia in clinical trials, share best practice and examine current obstacles** – This should continue the work of the PREDICT Consortium which considered this for older people more generally and was funded under the FP7 health research grant. Given the specific problems associated with low cohorts of older people with dementia in clinical trials and the issues surrounding rights and mental capacity, a charter specifically for older people with dementia is essential.

## The ILC-UK calls on the Members of the European Parliament to:

**Support the drafting and adoption of a United Nations convention on the human rights of older persons** - To promote international awareness of the situation of older persons including those with dementia and feed into the working group recently established to support this.

## The ILC-UK calls on Governments of the Member States to:

**Ensure the implementation and adequate resourcing of comprehensive national strategies to address all aspects of dementia.**

**Increase the number of health care professionals trained in dementia** - In order to enhance dementia screening, improve diagnosis rates and the provision of ongoing care.

**Create national centres of excellence in dementia research.**

**Develop networks and relationships between researchers from the public and private sphere** – This should include clinical, epidemiological, social and human sciences and provide incentivisation for the creation of interdisciplinary networks.

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**Ensure parity in funding for dementia research in line with other chronic diseases and the disease burden** –Given demographic change and burgeoning health and social care costs, dementia funding needs to be afforded the same priority as cancer and heart disease.

**The ILC-UK calls on NGOs, clinicians, industry and academia to:**

**Work with professional bodies that represent, regulate and are responsible for the training of GPs and other health care professionals to encourage more Continuing Professional Development in dementia and the exchange of best practice**

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# Annex one: EU estimates of people with dementia



EUROPEAN COMMISSION  
HEALTH AND CONSUMERS DIRECTORATE-GENERAL  
Directorate C - Public Health and Risk Assessment  
C2 - Health information

Estimated number of people (2006) with dementia

Countries	Age group	EuroCoDe				EURODEM			
		Total	Males	Females	As % of total population	Total	Males	Females	As % of total population
EU-27		7,302,318	2,357,843	4,944,476		6,486,561	2,434,341	4,052,220	
Belgium	30-95+	163,511	52,684	110,827	1.56	144,594	53,736	90,858	1.38
Bulgaria	30-95+	99,291	35,674	63,617	1.29	90,584	37,208	53,377	1.18
Czech Republic	30-95+	123,194	38,938	84,257	1.20	111,141	41,482	69,658	1.08
Denmark	30-95+	78,744	25,946	52,798	1.45	70,108	27,341	42,767	1.29
Germany	30-95+	1,368,330	418,037	950,293	1.66	1,214,085	438,135	775,951	1.47
Estonia	30-95+	17,825	4,528	13,296	1.33	15,831	4,801	11,029	1.18
Ireland (2002)	30-95+	37,417	12,946	24,471	0.96	33,719	13,565	20,154	0.86
Greece	30-95+	159,275	63,818	95,457	1.43	144,745	64,781	79,963	1.30
Spain	30-95+	690,992	233,210	457,782	1.57	611,734	236,844	374,890	1.39
France	30-95+	974,391	307,270	667,121	1.60	854,219	311,521	542,698	1.40
Italy (2004)	30-95+	1,012,819	325,390	687,429	1.74	896,688	335,383	561,305	1.54
Cyprus	30-95+	8,024	3,098	4,926	1.04	7,285	3,244	4,041	0.94
Latvia	30-95+	29,846	7,443	22,403	1.30	26,583	7,983	18,600	1.16
Lithuania	30-95+	40,619	11,194	29,425	1.20	36,423	11,897	24,526	1.07
Luxembourg	30-95+	5,814	1,829	3,985	1.23	5,178	1,904	3,274	1.10
Hungary	30-95+	131,995	39,696	92,300	1.31	118,169	41,781	76,388	1.17
Malta	30-95+	4,524	1,612	2,912	1.11	4,122	1,714	2,409	1.01
Netherlands	30-95+	210,666	68,099	142,567	1.29	187,912	71,382	116,530	1.15
Austria	30-95+	126,296	37,961	88,335	1.52	111,294	39,228	72,066	1.34
Poland	30-95+	391,344	123,101	268,242	1.03	354,160	127,603	226,558	0.93
Portugal	30-95+	153,386	52,761	100,625	1.45	137,403	54,240	83,163	1.30
Romania	30-95+	227,036	81,150	145,885	1.05	207,789	85,111	122,678	0.96
Slovenia	30-95+	25,380	7,451	17,929	1.26	22,822	7,949	14,872	1.14
Slovakia	30-95+	51,622	16,286	35,336	0.96	46,607	17,226	29,381	0.86
Finland	30-95+	77,516	23,306	54,210	1.47	68,738	24,432	44,306	1.31
Sweden	30-95+	161,327	54,198	107,129	1.78	141,948	55,370	86,577	1.56
United Kingdom	30-95+	931,134	310,217	620,918	1.54	822,679	318,480	504,199	1.36
Turkey (2000)	30-95+	253,367	102,744	150,623	0.37	242,771	116,682	126,090	0.36
Iceland	30-95+	3,319	1,242	2,077	1.09	2,967	1,267	1,700	0.97
Norway	30-95+	71,447	23,233	48,213	1.53	62,679	23,653	39,026	1.34
Switzerland	30-95+	125,614	40,582	85,032	1.68	110,654	41,823	68,831	1.48
<b>Grand total</b>		<b>7,756,065</b>	<b>2,525,644</b>	<b>5,230,421</b>		<b>6,905,633</b>	<b>2,617,766</b>	<b>4,287,867</b>	

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NB: Totals may not sum properly due to rounding.

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## Annex two: FP7 funded projects related to neurodegenerative disorders

Acronym	Title	FP7 theme and research area	EU funding (€) and project start date
<b>ADAMS</b>	Genomic variations underlying common behavioral diseases and cognition trait in human populations	HEALTH: Population genetic studies	3m 2009-02-01
<b>DOPAMINET</b>	Molecular networks of dopaminergic neurons in chordates	HEALTH: Multidisciplinary fundamental genomics and molecular biology approaches to study basic biological processes relevant to health and diseases	3m 2009-02-01
<b>EURIPIDES</b>	European research initiative to develop Imaging Probes for early In-vivo Diagnosis and Evaluation of response to therapeutic substances	HEALTH: Novel targeted imaging probes for early in vivo diagnosis and/or evaluation of response to therapy	7m 2008-02-01
<b>LUPAS</b>	Luminescent polymers for in vivo imaging of amyloid signatures	HEALTH: Activatable or smart in vivo imaging agents reporting on physico-chemical or molecular changes relevant to the diagnosis and/or monitoring of diseases	5m 2009-11-01
<b>PREDICTAD</b>	Find the best combination of biomarkers for Alzheimer's disease diagnostics from heterogeneous data and develop clinically useful tools integrating the optimal biomarker results	ICT: Virtual physiological human	3m 2008-06-01
<b>NAD</b>	Nanoparticles for therapy and diagnosis of Alzheimer disease	HEALTH: Nanotechnology-based systems for in-vivo diagnosis and therapy	10.9m 2008-09-01
<b>NANOGNOSTICS</b>	Quantum dot-based highly sensitive immunoassays for multiplexed diagnostics of Alzheimer's disease	HEALTH: Development of tools for sensitive and specific in vitro detection of proteins and their interactions for diagnostic, prognostic and monitoring purposes	4m 2009-10-01
<b>MEMOLOAD</b>	Neurobiological mechanisms of memory loss in Alzheimer's disease	HEALTH: Memory loss: underlying mechanisms and therapy	3m 2008-02-01
<b>MEMOSAD</b>	Memory loss in Alzheimer disease: underlying mechanisms and therapeutic targets	HEALTH: Memory loss: underlying mechanisms and therapy	3m 2008-01-01
<b>MEMSTICK</b>	Synaptic mechanisms of memory loss: novel cell adhesion molecules as therapeutic targets	HEALTH: Memory loss: underlying mechanisms and therapy	3m 2008-02-01
<b>MITOTARGET</b>	Mitochondrial dysfunction in neurodegenerative diseases: towards new therapeutics	HEALTH: Restorative approaches for therapy of neurodegenerative diseases	6m 2009-02-01

Acronym	Title	FP7 theme and research area	EU funding (€) and project start date
<b>MOLPARK</b>	Molecular mechanisms of neuronal restoration: novel approaches for Parkinson's Disease	HEALTH: Restorative approaches for therapy of neurodegenerative diseases	3.5m 2009-04-01
<b>NEUROPRO</b>	Oligopeptidase inhibitors in brain function and dysfunction: towards new therapeutic strategies for neuroprotection	HEALTH: Restorative approaches for therapy of neurodegenerative diseases	4.8m 2008-10-01
<b>NEURO.GSK3</b>	GSK-3 in neuronal plasticity and neurodegeneration: basic mechanisms and pre-clinical assessment	HEALTH: Restorative approaches for therapy of neurodegenerative diseases	3.6m 2008-10-01
<b>PLASTICISE</b>	Promotion of plasticity as a treatment for neurodegenerative conditions	HEALTH: Restorative approaches for therapy of neurodegenerative diseases	5.2m 2008-12-01
<b>NEUGENE</b>	Advanced gene therapy tools for treatment of CNS-specific disorders	HEALTH: Gene therapy tools targeting the central nervous system	3m 2008-10-01
<b>NEUROSTEMCELL</b>	European Consortium for Stem Cell Therapy for Neurodegenerative Diseases	Stem cell lines for cell-based therapies	11.6m 2008-12-01
<b>NEUROCYPRES</b>	Neurotransmitter cys-loop receptors: structure, function and disease	HEALTH: Structure-function analysis of membrane-transporters and channels for the identification of potential drug target sites	11m 2008-02-01
<b>LIPIDIET</b>	Therapeutic and preventive impact of nutritional lipids on neuronal and cognitive performance in aging, alzheimer's disease and vascular dementia	Food/Agri: Impact of diet on ageing	6m 2008-08-01
<b>Aaliance</b>	Ambient Assisted Living (AAL) solutions based on advanced ICT technologies for the areas of aging at work, aging at home and aging in the society	ICT: Independent Living	1m 2008-01-01
<b>CAPSIL</b>	International support of a common awareness and knowledge platform for studying and enabling independent living	ICT: Independent Living	€0.6m 2008-01-07
<b>CompanionAble</b>	Addresses the issues of social inclusion and homecare of persons suffering from chronic cognitive disabilities prevalent among the elderly, a rapidly increasing population group	ICT: Independent Living	€7.8m 2008-01-01
<b>SENIOR</b>	Aims to provide a systematic assessment of the social, ethical, and privacy issues involved in ICT and Ageing, to understand what lessons should be learned from current technological trends, and to plan strategies for governing future trends	ICT: Ethics of ICT and ageing	€1m 2008-01-01

Acronym	Title	FP7 theme and research area	EU funding (€) and project start date
<b>IMMUNE/MEMORY AGING</b>	Can immune system rejuvenation restore age-related memory loss?	ERC Advanced Grant - Neurosciences and neural disorders	€1.65m 2009-01-01
<b>NEURASYNC</b>	Academic-Industrial Training Network on Alpha-Synuclein-related Brain Diseases	Marie Curie Action: "Networks for Initial Training"	2.4m 2009-11-01

#### ERA-NETs

ERA-AGE II (ERA-NET) follows ERA-AGE, which was funded under FP6. The project aims to secure, for the long term, the future of the European Research Area in ageing research and launch Europe's first joint research programme on ageing.

## Annex three - FP6 funded projects related to neurodegenerative disorders (2002-2006)

Acronym	Brief Description	Research area	EU funding (€)
<b>EDAR</b>	Beta amyloid oligomers in the early diagnosis of AD and as marker for treatment response	Development of new diagnostics	0.6m
<b>GENEPARK</b>	Genomic biomarkers for Parkinson's disease	Development of new diagnostics	3m
<b>NEUROSCREEN</b>	Sensitive and differential blood and cerebrospinal fluid test for neurodegenerative dementia diagnosis	Development of new diagnostics	2.8m
<b>NEUROTas</b>	Microfluidic total analysis system for the early diagnostic of neurodegenerative disorders	Development of new diagnostics	2.5m
<b>EUROSCA</b>	European Integrated Project on spinocerebellar ataxias (EUROSCA): Pathogenesis, genetics, animal models and therapy	Studying the brain and combating diseases of the nervous system	9.5m
<b>APOPIS</b>	Abnormal proteins in the pathogenesis of neurodegenerative disorders	Studying the brain and combating diseases of the nervous system	9m
<b>cNEUPRO</b>	Clinical Neuroproteomics of Neurodegenerative Diseases	Studying the brain and combating diseases of the nervous system	3m
<b>EUSYNAPSE</b>	From molecules to networks: understanding synaptic physiology and pathology in the brain through mouse models	Studying the brain and combating diseases of the nervous system	8m
<b>INDABIP</b>	Innovative diagnostic approaches for biomarkers in Parkinson's disease	Studying the brain and combating diseases of the nervous system	1.6m
<b>MEMORIES</b>	Development, characterisation and validation of new and original models for Alzheimer's disease	Studying the brain and combating diseases of the nervous system	2.4m
<b>NCL-Models</b>	Dissecting neuronal degeneration: Neuronal ceroid lipofuscinoses from genes to function	Studying the brain and combating diseases of the nervous system	2m



<b>PROMEMORIA</b>	From cell-cell recognition to memory formation. New strategies for the treatment of dysfunctional plasticity, learning and memory	Studying the brain and combating diseases of the nervous system	9.7m
<b>RATstream</b>	European project on the characterisation of transgenic rat models for neurodegenerative and psychiatric diseases: Automated home cage analyses, live imaging and treatment	Studying the brain and combating diseases of the nervous system	3.4m
<b>STRESSprotect</b>	Inhibition of stress activated protein kinase signalling as a therapeutic strategy against excitotoxicity	Studying the brain and combating diseases of the nervous system	1.5m
<b>TAMAHUD</b>	Identification of early disease markers, novel pharmacologically tractable targets and small molecule phenotypic modulators in Huntington's disease	Studying the brain and combating diseases of the nervous system	3m
<b>ADIT</b>	Design of small molecule therapeutics for the treatment of Alzheimer's disease on the discovery of innovative drug targets	Rational and accelerated development of new, safer, more effective drugs	7.5m
<b>MIMOVAX</b>	Alzheimer's disease-treatment targeting truncated A $\beta$ 40/42 by active immunisation	Development and testing of new preventive and therapeutic tools	2.4m

## Networks

BrainNet Europe II (Network of Excellence)

Network of European brain and tissue banks for clinical and basic neuroscience

NeuroNE (Network of Excellence)

Molecular mechanisms of neuronal degeneration: from cell biology to the clinic.

ERA-AGE (ERA-NET) aimed to promote the development of a European strategy for research on ageing and, thereby, to enable Europe to gain maximum added value from investment in this field.

ERA-NEURON (ERA-NET) aims to create a strategically operating group of relevant research funding organisations in Europe to facilitate a coordinated implementation of research programmes in the area of research into brain diseases. ERA-NEURON has funded 12 projects in the area of neurodegeneration.

The following are projects funded by ERA-NEURON in the Joint Call 2008 "European research projects on neurodegenerative diseases of the central nervous system". The total funding was €10-11m for all projects. In each case funding came from National agencies.

Acronym	Title	Coordinator
<b>ADtest</b>	Role of proteases and their inhibitors in pathophysiology and diagnosis of Alzheimer Disease	Markus Glatzel (DE)
<b>EPITHERAPY</b>	An epigenetic approach towards the recovery of neuronal network plasticity and cognitive function in neurodegenerative disease	Andre Fischer (DE)
<b>ERMCC-NDEG</b>	The activity-driven ER-mitochondria Calcium Cycle (ERMCC) and protein misfolding in neurodegenerative diseases: finding targets for therapy	Julian Grosskreutz (DE)
<b>FamPD</b>	Identification of new genes causing familial forms of PD	Thomas Gasser (DE)
<b>heteropark</b>	Synthesis and validation of antiparkinsonian drugs targeting GPCR heteromers	Rafael Franco (ES)
<b>iPSoALS</b>	Modeling sporadic ALS in motor neurons by genetic reprogramming of patient skin fibroblasts	Georg Haase (FR)

<b>mGluRpatho</b>	Group III metabotropic glutamate receptors (mGluRs): from new molecules to therapeutic development for the treatment of Parkinson's disease	Marianne Amalri (FR)
<b>MIPROTRAN</b>	Transfer of misfolded protein as a pathogenetic mechanism in neurodegenerative disease	Patrik Brundin (SE)
<b>nEUROsyn</b>	Molecular mechanisms underlying synaptic dysfunction in prototypic neurodegenerative diseases related to protein misfolding	Fabrizio Tagliavini (IT)
<b>PARKCDNF</b>	Development of an experimental therapeutic strategy using the newly identified growth factor CDFN for treatment of Parkinson's disease	Kerstin Krieglstein (DE)
<b>PhysioIDBS</b>	Physiological mechanisms of Deep Brain Stimulation in Parkinson's disease	Jens Volkmann (DE)
<b>ProGen</b>	Protecting against neurodegeneration by somatic gene therapy	Thomas Arendt (DE)

## Appendix four: Neurodegeneration related projects funded under the Ambient Assisted Living Programme called related to demographic ageing in Europe (2008)

<b>Acronym</b>	<b>Brief Description</b>	<b>EU Funding (€)</b>
<b>AGNES</b>	The vision is to provide a user-sensitive ICT-based home environment that supports a person-centric care process by detecting, communicating, and meaningfully responding to relevant states, situations, and activities of the elderly person with regard to mild cognitive impairment or dementia.	<b>2.6m</b>
<b>ALADDIN</b>	A Technology Platform for the Assisted Living of Dementia Elderly Individuals and their Carers. The aim of the project is to utilise state-of-the-art in ICT in order to develop an integrated solution for the self-management of dementia patients, and develop innovative tools to support this procedure. This solution can be conceived as an integrated platform enabling distant monitoring of patient status and facilitating personalised intervention and adaptive care.	<b>1.4m</b>
<b>BEDMOND</b>	Behaviour Pattern Based Assistant for Early Detection and Management of Neurodegenerative Diseases. An assistant for the health professional, a daily behaviour information provider to early diagnose mild cognitive impairment (MCI) stages as a first step of neurodegenerative diseases, focused in elderly people while living at home.	<b>2.2m</b>
<b>CCE</b>	Connected Care for Elderly Persons Suffering from Dementia. The project supports the development of an open, standardised, integrated European platform to deliver connected ICT-based assistive living solutions for the elderly.	<b>2.2m</b>
<b>HELP</b>	Home-based Empowered Living for Parkinson's Disease Patients. The project integrates a complex system that dynamically monitors and treats Parkinson's Disease patients. The system comprises a non-invasive intra-oral drug delivery device, a pump to deliver rescue medication, a PAN (Personal Area Network) to gather user's environment information, a telecommunication and services infrastructure to transfer information between the user and an automated system and a remote point-of-care unit to supervise the patients, €2.5m funding.	<b>2.5m</b>
<b>HERA</b>	The HERA project aims at providing a platform with cost-effective specialised assisted living services for the elderly people suffering from mild Alzheimer or cardiovascular diseases with identified risk factors, which will significantly improve the quality of their home life, extend its duration and at the same time reinforce social networking, funding.	<b>1.2m</b>
<b>HOPE</b>	The Hope project addresses elderly people that suffer from Alzheimer's disease to achieve a richer lifestyle. An ICT system will enable persons to perform activities they were not able to do before and which are important for their daily personal life. The proposed system provides a basis for integrating further services, e.g. control of the home environment, funding.	<b>1.1m</b>

<b>ROSETTA</b>	ROSETTA will help community dwelling people with progressive chronic disabilities (i.e. Alzheimer's Disease and Parkinson's Disease) to retain their autonomy and quality of life as much as possible and to support their (in)formal caregivers by developing and providing an ICT system that offers activity guidance and awareness services for independent living, funding.	<b>2.3m</b>
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## Annex five: ESFRI projects

The objective of ESFRI is to provide an overview of the needs for research infrastructures of pan-European interest in different fields of science and technology. Launched in April 2002, it aims in particular to support a coherent and strategy-led approach to policy-making on research infrastructures in Europe and to facilitate multilateral initiatives leading to better use and development of research infrastructures. The forum brings together a representative of the European Commission with ministerially appointed Member States representatives who are decision-makers on research infrastructures policy in their country.

Projects identified on the first ESFRI Roadmap are now in a preparatory phase, which is the first step in implementing an ESFRI project. The purpose of the preparatory phase is to establish the legal, organisational and financial framework for the construction and operation of the new facility.

**ESFRI Initiatives:** infrastructures in the preparatory phase which will underpin research in many areas of health.

Acronym	Brief Description	Website
<b>EATRIS</b>	The European Advanced Translational Research Infrastructure in Medicine is a distributed pan-European infrastructure consisting of a network of biomedical translation research centres across Europe.	<a href="http://www.eatris.eu/">http://www.eatris.eu/</a>
<b>BBMRI</b>	European Biobanking And Biomolecular Resources is a network with ultimately single point access to hundreds of European biobanks using common minimum standards.	<a href="http://www.biobanks.eu">www.biobanks.eu</a>
<b>Infrafrontier</b>	Infrastructure for Phenomefrontier and Archivefrontier comprises infrastructure networks for large-scale and comprehensive phenotyping and archiving of mouse models serving the European genetics and biomedical research community for the benefit of human health.	<a href="http://www.emma.rm.cnr.it">www.emma.rm.cnr.it</a>
<b>ECRIN</b>	Infrastructures For Clinical Trials And Biotherapy is a European network with a focus on the harmonisation and execution of clinical trials and provision of integrated 'one-stop shop' services to investigators and sponsors in multinational studies	<a href="http://www.ecrin.org">www.ecrin.org</a>
<b>Integrated Structural Biology Infrastructure</b>	Integrated Structural Biology Infrastructure will link the information obtained by the major structural biology methods with state-of-the-art cell biology techniques to provide a dynamic picture of key cellular processes at all scales	<a href="http://www.strubi.ox.ac.uk">www.strubi.ox.ac.uk</a>
<b>ELI</b>	Upgrade Of European Bioinformatics Infrastructure, ELI, will be a secure and rapidly-evolving platform for data collection, storage, annotation, validation, dissemination and utilisation, consistent with the unique requirements of shared resources in the life sciences.	<a href="http://www.ebi.ac.uk">www.ebi.ac.uk</a>

## Annex six: List of Participants

Surname	Name	Organisation	Role
Aldinhas de Freitas Ferreira	Maria da Conceição	Pfizer	Senior European Brand Manager
Anderson	Robert	Eurocarers	President
Audibent	Patrice	European Parliament	Assistant to Frédérique Ries MEP
Augus	Abbey	European Parliament	Assistant to Karin Kadenbach MEP
Bamford	Sally-Marie	ILC-UK	Senior Reseacher
Banerjee	Sube	King's College London	Professor of Mental Health and Ageing
Bogdanovic	Nenad	Pfizer Europe	Senior Medical Manager
Boyle	Robert		
Burns	Alistair	Department of Health	Clinical Director of Dementia
Davies	Chris	European Parliament	MEP
Georges	Jean	Alzheimer's Europe	Executive Director
Gombault	Béatrice	King Baudouin Foundation	Project Manager
Greengross	Baroness Sally	ILC-UK	Chief Executive
Grut	Eva	Pfizer Europe	Senior Director, Head of EU Representation Office
Hargreaves	Ruth	Pfizer Europe	Senior Director
Isaac	Maria	European Medicines Agency UK	Consultant Psychiatrist & Senior Lecturer Human Medicine
Leners	Jean-Claude	EUGMS	Geriatrician
Lupton	Carol	Department of Health UK	Senior Principal Research Officer
Lustman	Florence		Chief Co-ordinator of the French Alzheimer's Plan
McGrath	Clare	Pfizer	Senior Director Evidence Based Strategies
O'Neill	Maureen	European Economic and Social Committee	UK Member
Peacock	Emma	Pfizer	UK Government Affairs Manager
Peters	Oliver	Charité - Campus Benjamin Franklin	Head of the Department of the Gerontopsychiatric Ambulant Clinic and Memory Consultation
Pickett	James	Alzheimer's Society	Research Grants Officer
Pietikäinen	Sirpa	European Parliament	MEP
Prince	Martin	King's College London	Professor of Epidemiological Psychiatry

Ryan	Michael	Pfizer	Team Lead of the Alzheimer's Active Immunotherapy Development Programme
Sarah	Deblock	European Parliament	Assistant to Chris Davies MEP
Siba	Noreen	ILC-UK	Managing Director
Simunkova	Marta		Czech Physician and Journalist
Taylor	Rebecca	ILC-UK	Senior Researcher
Valtanen	Aino	European Parliament	Assistant to Sirpa Pietikainen MEP
Visser	Pieter Jelle	University of Maastricht	Alzheimer Centre, Department of Psychiatry, School for Mental Health and Neuroscience
Wadoux	Julia	Age - The European Older People's Platform	Policy Officer for Health and New Technology and Project Manager
Yannakoudakis	Marina	European Parliament	MEP



## Annex seven: Meeting agenda

- 09.00 – 09.05: Introductions

09.05 – 09.10: Welcome & opening remarks by host and co-chair: Chris Davies MEP, Introduction by co-chair, Baroness Sally Greengross, International Longevity Centre,

- Speakers:

- 09.10 – 09.20: **Jean Georges**, Executive Director of Alzheimer's Europe - *Overview of EU Landscape and Dementia*
- 09.20 – 09.30: **Pieter Jelle Visser**, Clinical Epidemiologist at the Alzheimer Centre, Department of Psychiatry, School for Mental Health and Neuroscience, University of Maastricht -*Alzheimer research funding on the European level, the Joint Programming Initiative on Neurodegeneration*
- 09.30 – 09.40: **Florence Lustman**, Chief Co-ordinator of the French Alzheimer's Plan – *Implementing a comprehensive dementia strategy: lessons from the French Alzheimer's plan, how to integrate research into National Action Plans*
- 09.40 – 09.50: **Michael Ryan**, Team Lead, Alzheimer's Active Immunotherapy Development Programme, Pfizer – *The challenges of Alzheimer's disease research*
- 09.50 – 10.00: **Alistair Burns**, Clinical Director of Dementia at the Department of Health – *What are the top priorities for new research and lessons from the UK experience*
- 10.00 – 10.40: Introduction to questions Chris Davies MEP
  - What are the top priorities for new research in Europe?
  - What are the barriers to effective (good quality/high impact) research and how can these barriers be overcome?
  - How do we co-ordinate research activities and actions between EU Member States?
- 10.40 – 11.00: Chris Davies MEP and Baroness Greengross.
- Development of recommendations: What needs to happen at the National and EU level? What actions or initiatives are needed and which actors and/or institutions are ideally situated to promote this change?





ILC-UK  
11 Tufton Street  
London  
SW1P 3QB  
Tel : +44 (0) 20 7340 0440  
[www.ilcuk.org.uk](http://www.ilcuk.org.uk)