



# European Union public health action in the field of Alzheimer's disease and other dementias

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## Background

- The most common causes of dementia in EU are Alzheimer's disease (about 50-70% of cases), the successive strokes which lead to multi-infarct dementia (about 30%); other causes are Pick's disease, Binswanger's diseases, Lewy-Body dementia and others.
- Data on the prevalence on Alzheimer's disease and other dementias are available across the EU collected by [Alzheimer Europe](#). However, these estimates must be treated with caution, as the type of source varies considerably in scale and accuracy by Member State. An estimated 7.3 million Europeans (in 27 Member States) between 30 and 99 years of age suffered from different types of dementias in 2006 (14.6 per 1 000 inhabitants). Within this group, more women (4.9 million) than men (2.4 million) were affected.

## The basis for actions at European level

- **Article 168 of the EC Treaty provides that Community action is to complement national policies and be directed towards improving public health, preventing human illness and diseases, and obviating sources of danger to human health,**
- **Community action in the field of public health shall respect the responsibilities of the Member States for the organisation and delivery of health services and medical care,**
- **The Work Plan for 2005 for the implementation of the programme of Community action in the field of public health (2003-2008) included for the first time a specific reference to the need of information and definition of indicators on the prevalence, treatments, risk factors, risk reduction strategies, cost of illness and social support as well as what constitutes a "healthy brain lifestyle" related to Alzheimer disease (AD) and other dementias. Similar reference in all the following Work Plans.**
- **The White Paper COM(2007) 630 final "Together for Health: A Strategic Approach for the EU 2008-2013" of 23 October 2007 developing the EU Health Strategy also identifies the better understanding of neurodegenerative diseases such as Alzheimer's as important needs to address**
- **The European Commission's FP7 (2007–2013) emphasize collaborative research with a specific sub activity on "Research on the brain and related diseases, human development and ageing". Particular emphasis will be placed on translational research, for bringing knowledge from bench to bedside and for development of new drug targets. In addition to the proposed budget increase for European research in FP7 compared to FP6, it is expected that FP7 will offer a broad range of possibilities to address Alzheimer disease research at the EU level**

## Past European initiatives to take into account

- The conclusions of the project EuroCode (European Collaboration on Dementia), coordinated by Alzheimer Europe, selected for funding in 2005 by the Public Health Programme and finished in 2009.
- The conclusions of the 'Dementia in Europe Yearbook' 2006, 2007, 2008 and 2009 from Alzheimer Europe with the support of the European Commission providing European overviews of the prevalence of dementia, the reimbursement systems for anti-dementia drugs and the provision of home care, as well as a detailed description of these findings for 31 European countries (the 27 Member States of the European Union and Iceland, Norway, Switzerland and Turkey).
- The Written Declaration on priorities in the fight against Alzheimer's disease- European Parliament- January 2009.
- Some articles in the future Directive of the European Parliament and of the Council on the application of patients' rights in cross-border healthcare.
- The adoption in 2008 of the European Pact for Mental Health and well-being as a symbol of the determination to exchange and work together on mental health opportunities and challenges related to older populations.
- The recent Peer Review on *Alzheimer's and other related diseases: coping with behavioural disorders in the patient's home* in the framework of the Peer Review in Social Protection and Social Inclusion and Assessment in Social Inclusion (DG EMPL, European Commission).

## Ongoing European initiatives to be developed

- During French Presidency the Council adopted on December 2008 the [Council Conclusions on public health strategies to combat neurodegenerative diseases associated with ageing and in particular Alzheimer's disease](#) addressed to Member States and the Commission in order to recognise that these diseases constitute a priority for action in the context of the ageing of the EU's population, to take into account of the potential consequences of the increase of these diseases for the financial sustainability of health and social protection systems, to reflect together on existing quality criteria for the care of patients and the support of carers, to consider ways of developing them further and calling the Commission to adopt an initiative in 2009 to combat these diseases.
- Following this, the Commission has adopted the 22nd July 2009 the [Communication from the Commission COM\(2009\) 380/4 to the European Parliament and the Council on a European initiative on Alzheimer's disease and other dementias](#). The EU would support national efforts in four key areas: prevention, including measures to promote mental well-being, and support early diagnosis, coordinating research across Europe, spreading best practice for treatment and care and developing a common approach to ethical questions – rights, autonomy, and dignity of people with dementia.

## Ongoing European initiatives to be developed

- At the same time the Commission adopted a proposal addressed to the Council, **Proposal for a Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer's, through joint programming of research activities**, inviting the MS to work towards a common vision of how research cooperation and coordination at European level can help us to understand, detect, prevent and combat Neurodegenerative diseases, especially Alzheimer's disease, and develop a Strategic Research Agenda (SRA) establishing medium to long-term research needs and objectives, including an implementation plan establishing priorities, milestones and timelines.
- The Commission has also adopted on 15th April 2010 a **wide research initiative to tackle neurodegenerative diseases such as Alzheimer's and Parkinson's Disease**. This is the first of the new European Union Joint Programming initiatives. To achieve this goal, 24 European countries, sharing a common vision, have decided to work together in an unprecedented collaborative initiative in research which is seeking to align their scientific competencies, medical strengths and social approaches to tackle the challenge.

## Implementing the public health initiatives

To implement these objectives with the cooperation of the Member States and patient's organisations the Commission :

- The Commission has selected for funding in 2009 an **Operational Grant** to be implemented by Alzheimer's Europe;
  - **08/03/2010** [Alzheimer Europe organizes the first meeting of the working group on assistive technology for people with dementia](#)
- A **Joint Action between Commission and Member States** (to be financed in 2010 by the Health Programme) having as main objectives the actions specified in the Commission Communication as well as the results of the EuroCode (European Collaboration on Dementia) Project supported by the Public Health Programme. A **Panel of Experts on Alzheimer's disease and other dementias** met last 14th December 2009 in order to prepare this Joint Action.
- The Commission will support and highlight the next **Alzheimer Europe Conferences** (Luxembourg, 30 September-2 October 2010 and Warsaw, 6-8 October 2011) and a **Dementia and Ageing Conference** (Brussels, November 2010).

## Implementing these initiatives

### What's a Joint Action between Commission and Member States ?

- The joint action participants must be bodies to which Member States have attributed tasks concerning public health activities, as appropriate to the area covered in the call for proposals.
- Adequate number of Member States participating ensuring that a geographical coverage of the action is appropriate with regard to its objectives, explaining the role of the eligible countries as partners and the relevance of the project resources or target populations they represent.
- Clarity and quality of the objectives, work plan, organisation and description of the results and benefits expected as well as communication and dissemination strategies.
- Balanced participation of proponents in the activities planned.
- Community contribution for joint actions shall not exceed 50 %, except in cases of exceptional utility, where Community contribution shall not exceed 70 %.



## Implementing these initiatives

Objectives for the Commission of the **Joint Action between Commission and Member States:**

- To incorporate the 'dementia dimension' into the European Union's ongoing and future actions on health prevention, especially those related to cardiovascular health and physical activity.
- To produce a citizen's summary of dementia prevention measures under a 'Healthy brain lifestyle' set of recommendations.
- To include the 'dementia dimension' in flexible European policies on retirement and in the framework for action on older people in the European Pact for Mental Health and Wellbeing.
- To map the existing and emerging good practices related to treatment and care for persons suffering from Alzheimer's disease and other forms of dementia and to improve the dissemination and application of such practices (using, when possible, the Structural Funds).
- To develop, by means of the Open Method of Coordination, quality frameworks for medical and social care services for people with dementias.
- To use facilities provided for in the EU Disability Action Plan (DAP) 2003-2010 to

## Implementing these initiatives

Objectives for the Commission of the **Joint Action between Commission and Member States:**

- To improve epidemiological data on Alzheimer's disease and other dementias, implementing the conclusions of the EuroCoDe Project;
- To use the planned European Health Examination Survey to provide new Europe-wide data on the prevalence of people with early cognitive deficiencies;
- To map the existing and emerging good practices related to treatment and care for persons suffering from Alzheimer's disease and other forms of dementia and to improve the dissemination and application of such practices (using, when possible, the Structural Funds).
- To establish, using the facilities provided by the Health Programme, a European Network for rights and dignity of people with dementia, which should formulate recommendations on dignity, autonomy and social inclusion, and to share best practices on respecting the rights of vulnerable adults and tackling patient abuse.

## Implementing these initiatives

Structure of the **Joint Action between Commission and Member States:**

**Coordination: Haute Autorité de Santé (HAS) - France**

**Thérèse HORNEZ, Catherine Helmer, Pr Jean-Francois Dartigues**

- **Assessment of available population-based epidemiological studies on dementia, and information systems including data allowing the survey of Dementia**
  - Available epidemiological data on dementia prevalence, incidence, access to care and predictors of institutionalisation will be analysed. (Un)Published data which fulfil specific quality criteria will be analysed. Rates of conversion from MCI to dementia will be evaluated. Data on diagnosis, medical treatment and social services for people with dementia and their families will be assessed.
- **Definition of best criteria and best practices for improving the collection of epidemiological data**
  - The quality of available epidemiological data varies enormously. This variability makes it difficult to compare data from different settings. A multi-professional group will define best criteria and best practices for improving the collection of epidemiological data.

## Implementing these initiatives

Structure of the **Joint Action between Commission and Member States:**

**Coordination: Haute Autorité de Santé (HAS) - France**

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- **Assessment of current recommendations for the diagnosis of dementia and of the diagnosis systems**
  - Assessment of recommendations for the diagnosis of dementia will be performed in order to access to a common definition with operational criteria. Assessment of health care systems for diagnosis will be performed in order to formulate recommendations improving early diagnosis.
- **Assessment of practices of care and practices in training**
  - Assessment of practices of care allowing to define good practices of care. Assessment of practices in training allowing to define good practices of training.
- **Overview of existing advance declarations of will and of good practices in assessing the competence of cognitively impaired elderly.**
  - Overview of existing advance declarations of will in EU members states and practices of use of them for AD and demented people. Overview of good practices that help to assess the competence of elderly people with cognitive impairments

## Implementing these initiatives

Structure of the **Joint Action between Commission and Member States:**

**Coordination: Haute Autorité de Santé (HAS) - France**

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### Indicators and outcomes

- Constitution of a register of available epidemiological data / Systematic review on epidemiological data.
- Protocol that defines the best criteria and the best practices for epidemiological data collection / Improvement of collection of epidemiologic data in European countries
- Assessment of existing preventive actions and their effectiveness / Improvement of preventive actions
- Common definition of operational criteria of diagnosis and assessment of health care systems for diagnosis./ Improvement of health care systems to improve early diagnosis
- Report on Advance Declarations of will and on competence assessment in dementia./ Improvement of practices respecting the rights of people cognitively impaired.

## Implementing these initiatives

Structure of the Carers Interest Group meeting: EU2020 and carers

### Coordination: European Parliament Interest Group on Carers

- The December 2009 Council conclusions, which call for a European action programme on healthy and dignified ageing (as a result of the September Swedish presidency conference on that topic). Carers and their issues will certainly feature in this action programme; the need for better dialogue and cooperation between professional and informal care providers will be another important focus.
- The European Social Fund provides funding for training; training of carers would certainly be considered part of this.
- The upcoming Green paper on pensions will also raise issues in relation to social security entitlements. While social security entitlements remain the responsibility of the member states, the Green paper is based on two concerns, i.e. the impact of the current crisis on pensions and the pressure on social security systems as a result of demographic ageing. Mobility of pensions is another tricky issue, and the debate on this topic might also be revived in the Council.
- While EU2020 does not specifically address carers issues: apart from the inclusion strand, which would offer the possibility of focusing on fighting inequalities (also in terms of access and quality of services), the 'smart' and 'green' strands of the strategy would address innovation, knowledge and education – also in health and care provision – as well as living conditions.
- Current discussions on designating 2012 as the European Year on Active Ageing and Solidarity between the Generations.

## Implementing these initiatives

European Year on Active Ageing and Solidarity between the Generations

**Coordination: European Commission (INFSO, EMPL, SANCO)**

- **Current discussions are ongoing on designating 2012 as the European Year on Active Ageing and Solidarity between the Generations.**
- **The Commission is considering to launch additional initiatives in the context of this future European Year of Active Ageing thus contributing to the objectives of growth as outlined in the Europe 2020 agenda.**

## Implementing these initiatives

**The PharmaCOG (Prediction of Cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development)**

**Coordination: Université de la Méditerranée (Marseille, France)**

- Will create a new and unique partnership between the European Commission and the EFPIA (European Federation of Pharmaceutical Industries and Associations). The PHARMA-COG consortium consists of 30 public (Universities, Research Centres, Hospitals) and private partners as well as Alzheimer Europe,
- PHARMA-COG will also work closely with the EMEA, as an associated partner of this project, to share project progress and discuss the implications for drug development in Europe.
- With a co-funding of € 9M by the Innovative Medicines Initiative of the European Union and € 13M by the EFPIA partners, it is the most ambitious project tackling Alzheimer's disease ever funded at European level in order to validate tools necessary to streamline Alzheimer's disease drug discovery and accelerate effective medicine to patients.
- Bringing together European experts in technologies fully translatable from animal to human, experts in translational medicine, drug discovery and mathematical modelling, PHARMA-COG proposes to accelerate this validation using a 'MATRIX' approach i.e. conducting parallel experiments in animals and human using a comprehensive and standardised battery of behavioural, neurophysiological, morphological/functional imaging, and biochemical endpoints to:



## Implementing these initiatives

The PharmaCOG (Prediction of Cognitive properties of new drug candidates for neurodegenerative diseases in early clinical development)

**Coordination: Université de la Méditerranée (Marseille, France)**

- The combined size and expertise of PHARMA-COG provides a truly unique opportunity to validate the tools required to fundamentally change the drug discovery process in AD and accelerate efficacious drug to patients across Europe.
- Workpackage 5 of PharmaCog (Identification of biomarkers sensitive to disease progression: Clinical Studies - European ADNI) is about the development of markers to track the progression of the disease in humans that are homologous to those used in animal models. WP5 uses as core markers those harmonized in the context of the North American ADNI and expands them with specific structural, functional, microstructural, molecular, central, and peripheral markers. WP5 is thus labeled as the “European ADNI
- By the end of this 5-year project PHARMA-COG will have a) validated the tools necessary to streamline AD drug discovery and accelerate effective medicine to patients, b) set the standard for European drug discovery providing optimised and validated protocols c) provided the infrastructure to sustain world class drug discovery in Europe and d) disseminate the obtained results from health professionals to patients.

## Implementing these initiatives

Structure of the **Joint Programming Initiative on Neurodegenerative diseases between Commission and Member States:**

Coordination: **Fondation de coopération scientifique sur la maladie d'Alzheimer et les maladies apparentées - France**

- The Commission has also adopted on 15th April 2010 a **wide research initiative to tackle neurodegenerative diseases such as Alzheimer's and Parkinson's Disease**. This is the first of the new European Union Joint Programming initiatives. To achieve this goal, 24 European countries (20 MS + AL, NO, TR and CH), sharing a common vision, have decided to work together in an unprecedented collaborative initiative in research which is seeking to align their scientific competencies, medical strengths and social approaches to tackle the challenge.
- Today in the EU 5% of Dementia research funds are EU funds (FP7), 10% are intergovernmental conventions, 85% are purely national.
- Management Board since 18th June 2009 Chaired by France and vice-chaired by Sweden.

## Implementing these initiatives

Structure of the **Joint Programming Initiative on Neurodegenerative diseases between Commission and Member States:**

**Coordination: Fondation de coopération scientifique sur la maladie d'Alzheimer et les maladies apparentées - France**

- The European Commission will be supporting the work of the initiative through a coordinating action with an EU contribution of close to € 2 million. The joint programming initiative will build on existing collaboration in Europe. The European Commission has contributed to fostering such collaboration. For example, during Research Framework Programme 6 (FP6), 28 projects on neurodegenerative diseases were funded with an EU contribution of € 136 million. So far in FP7, 34 projects have been funded with an EU contribution of € 159 million. The Commission will continue launching activities that are complementary to the work of the JPND.
- Both European Commission General Directorates leading these actions, DG SANCO for the Joint Action on the public health actions, and DG RTD for the Joint Programming on research, will work in close cooperation to establish the synergies and complementarities between both actions.



# Research on Neurodegenerative Diseases and Alzheimer's

## Basic

- Research on genetic susceptibility and genome-wide association studies (GWA)
- Developing animal models
- Basic research on pathophysiology
- Development of new imaging technologies and new biomarkers
- Studying early onset forms of Alzheimer's disease and related dementia
- Development of new treatment strategies
- Coordinate biobanks for blood samples, cerebro-spinal fluid (CSF), brain tissue
- Launching or integrating large population cohorts or registries

## Medical

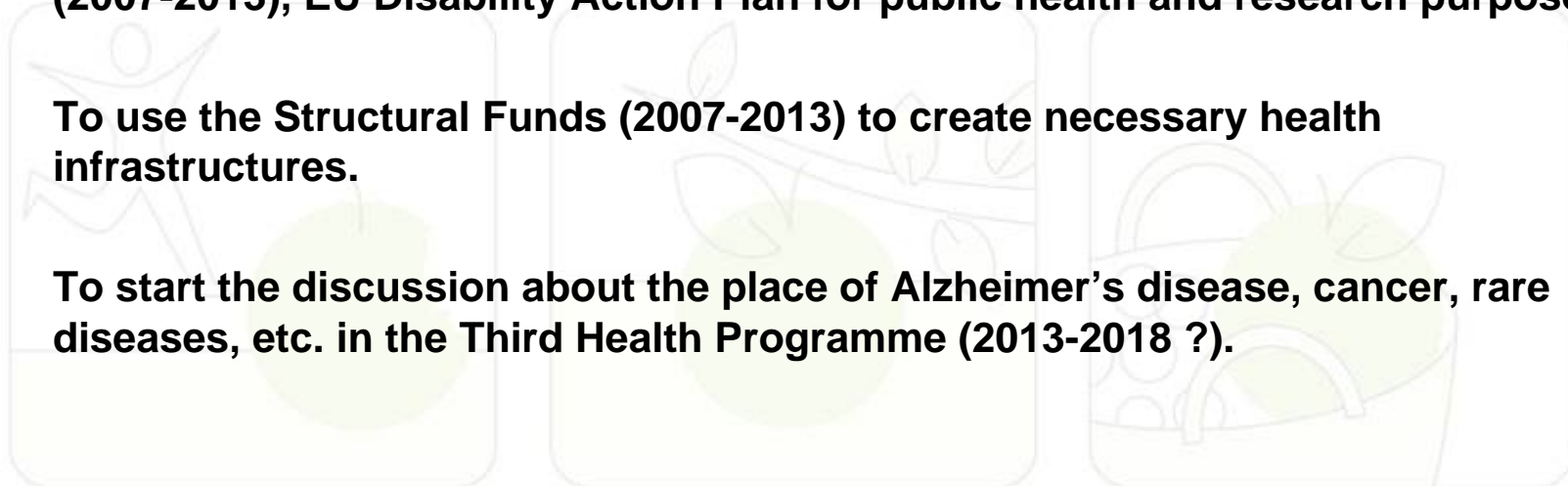
- Early diagnosis using a multidisciplinary approach
- Prevention to reduce the burden of dementias
- Investigator-driven clinical trials
- Standardisation of diagnostic criteria and diagnostic instruments

## and Social Services

- Comparison of different systems and identification of best practice
- Home automation, smart homes and domotics
- Ethics and health economics

## Sustainability in the long-term

- **Continue to use facilities provided by the Health Programme (2008-2013), FP7 (2007-2013), EU Disability Action Plan for public health and research purposes.**
- **To use the Structural Funds (2007-2013) to create necessary health infrastructures.**
- **To start the discussion about the place of Alzheimer's disease, cancer, rare diseases, etc. in the Third Health Programme (2013-2018 ?).**



## Further information

- [http://ec.europa.eu/health/ph\\_information/dissemination/diseases/alzheimer\\_en.htm](http://ec.europa.eu/health/ph_information/dissemination/diseases/alzheimer_en.htm)

