



EUROPEAN
COMMISSION

European
Research Area

“Joint Programming”

A European pilot initiative for combating neurodegenerative diseases, in particular Alzheimer’s

Manuel Hallen, MD
Head of Unit ‘Medical & Public Health Research’
DG RTD, European Commission





EUROPEAN
COMMISSION

European
Research Area

On 22 July 2009, the Commission adopted a proposal for a Council Recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer's, through joint programming of research activities (COM 2009, 379/3)



The Recommendation invites the Member States to work towards establishing:



A common vision of how cooperation and coordination at EU level can help us to understand, detect, prevent and combat neurodegenerative diseases, in particular Alzheimer's disease



A strategic research agenda establishing medium to long term research needs and objectives in the area of neurodegenerative diseases



A management structure to monitor the implementation of the Strategic Research Agenda



EUROPEAN
COMMISSION

European
Research Area

Why the focus on neurodegenerative diseases, in particular Alzheimer's disease?



A major issue for Public health in Europe



A field of growing priority for research funding in Europe



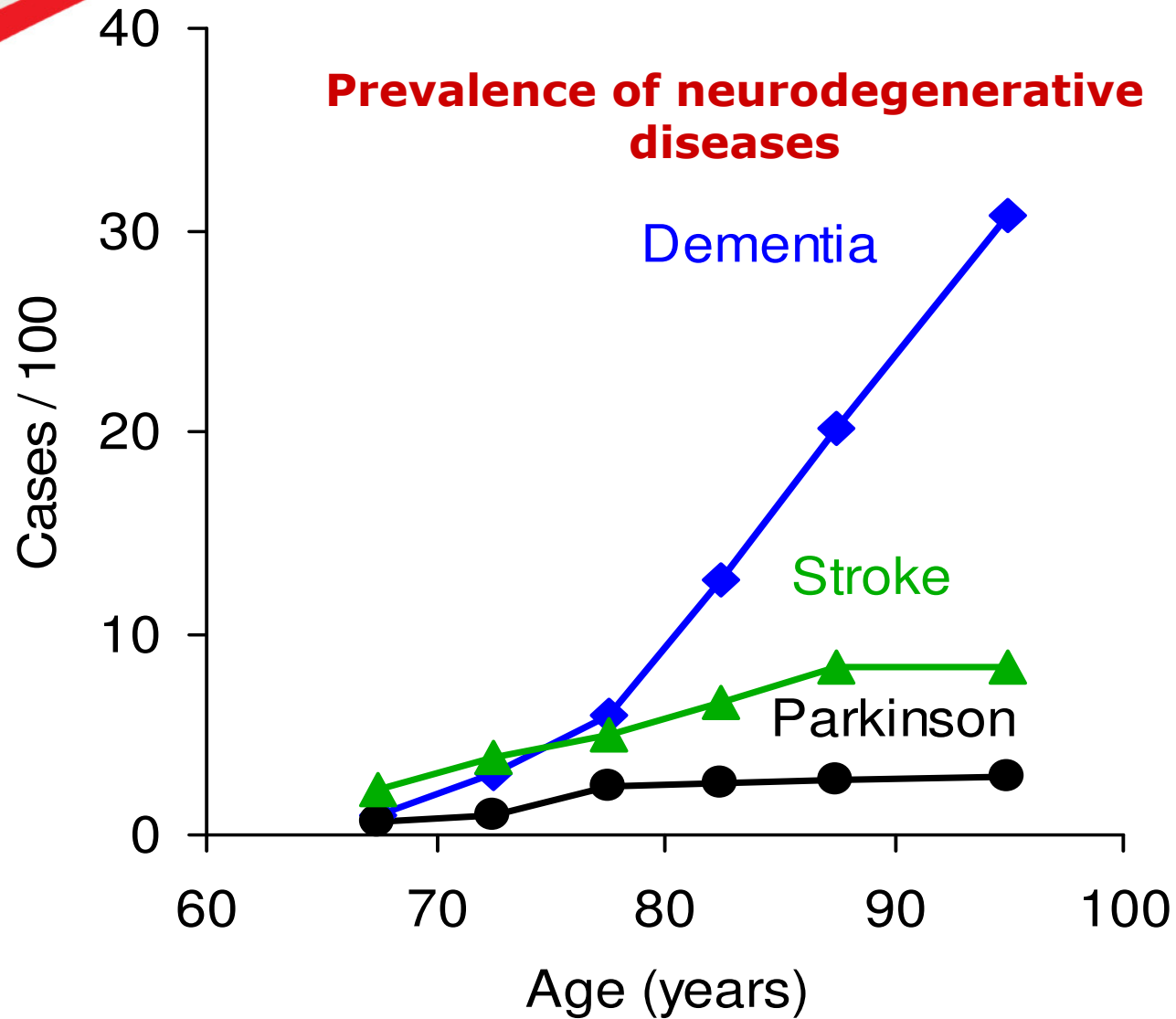
A substantial research effort is needed



The benefits of better coordination



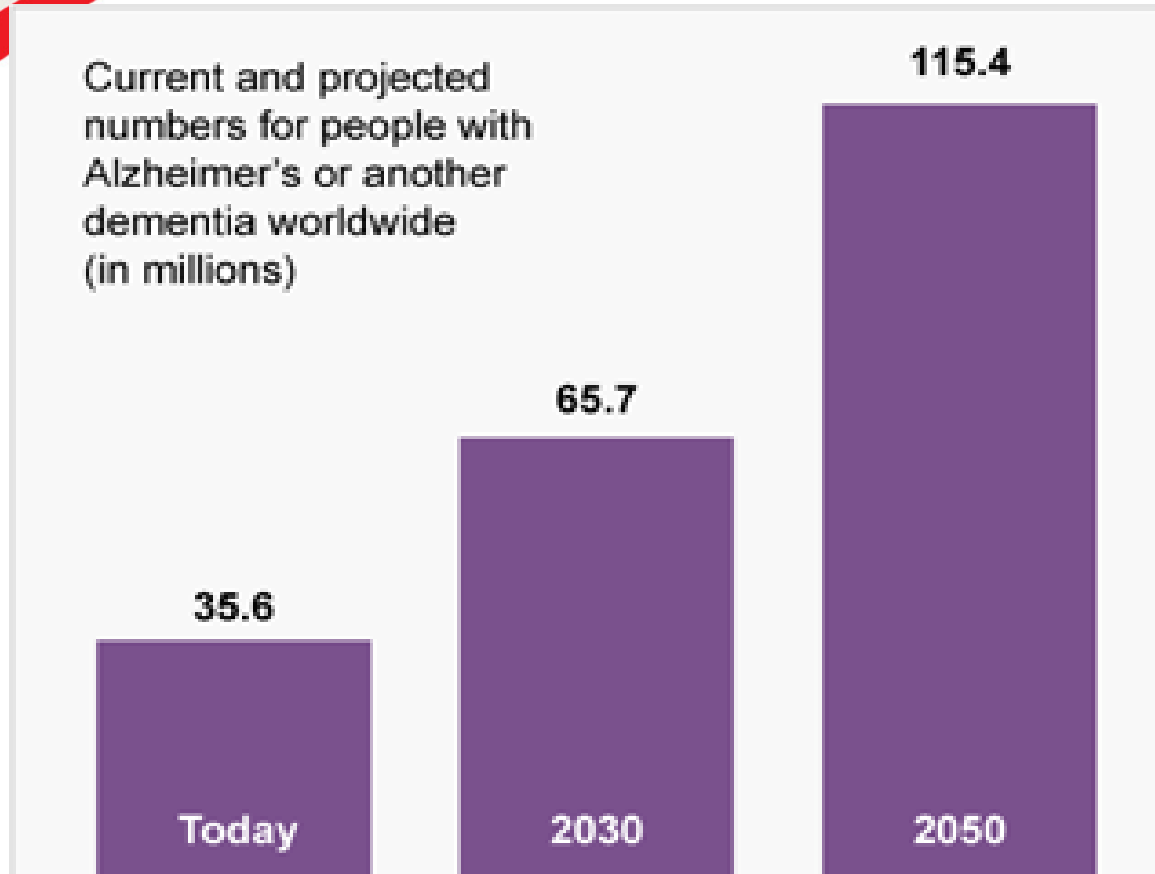
A major issue for public health in Europe



From Rocca W et al, Eurodem Study

A major issue for public health in Europe

Alzheimer's and related dementias: a global burden



Source: 2009 *World Alzheimer Report*, from Alzheimer's Disease International (ADI), a London-based nonprofit, international federation of 71 national Alzheimer organizations including the Alzheimer's Association.

- Alzheimer's is the most prevalent neurodegenerative disorder
- It accounts for 50-70% of all dementias in Europe
- It is the 4th most common cause of burden of disease in high-income countries

A major issue for public health in Europe



7.3 million Europeans suffer from Alzheimer's disease and related forms of dementia (12.5 per 1000 inhabitants).



These are terminal conditions, but people can live and progressively deteriorate for 7-12 years after initial diagnosis.



These conditions are devastating for patients, relatives and family carers. It is estimated that 19 million Europeans are directly concerned with the disease on a daily basis.



The total direct and informal care costs of Alzheimer's and other dementias in 2005 amounted to € 130 billion for EU-27, 56% of costs were for informal care.



EUROPEAN
COMMISSION

European
Research Area

Why the focus on neurodegenerative diseases, in particular Alzheimer's disease?



A major issue for Public health in Europe



A field of growing priority for research funding in Europe



A substantial research effort is needed



the benefits of better coordination



A field of growing priority for research funding in Europe



Member States are adopting comprehensive national strategies and plans to tackle these diseases. In many countries, Alzheimer's disease is becoming one of the emerging research priorities



In 2005, the total spending on brain research in Europe was some € 4,1billion. Of this, € 855 million came from the public sector



The EU Research Framework Programmes have paid growing attention to neurodegenerative diseases, in particular Alzheimer's. € 136 million were allocated for the period 2002-2006. € 102 million have been devoted to this area for the period 2007-2009, 1/3 of all investment provided for brain research in FP



EUROPEAN
COMMISSION

European
Research Area

Why the focus on neurodegenerative diseases, in particular Alzheimer's disease?



A major issue for Public health in Europe



A field of growing priority for research funding in Europe



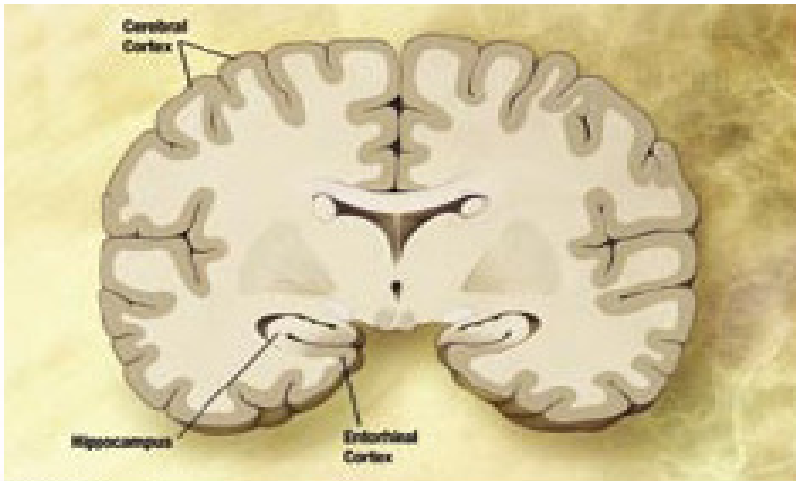
A substantial research effort is needed



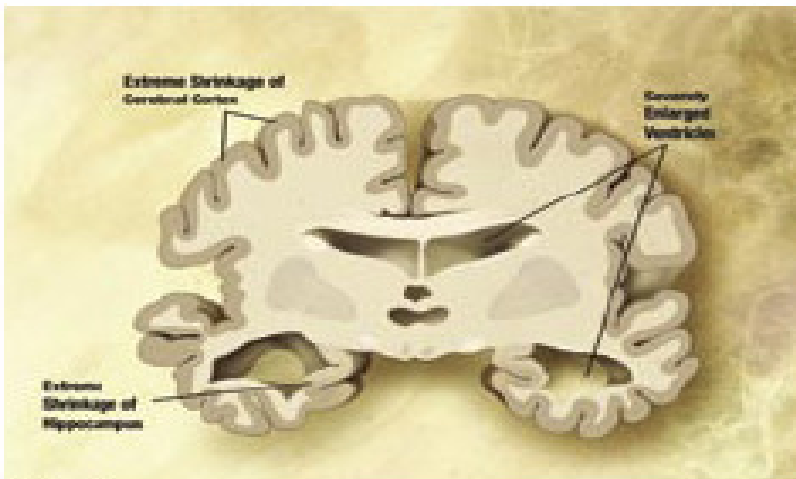
The benefits of better coordination



A substantial research effort is needed



Healthy brain



AD brain

- Currently there is no treatment available able to slow or stop the deterioration of brain cells
- AD is under-diagnosed in the EU
- Diagnosis is usually made at a too late stage to make best use of treatments
- Risk factors are not well known



Lifetime Influences

Genes
Environment
Systemic factors

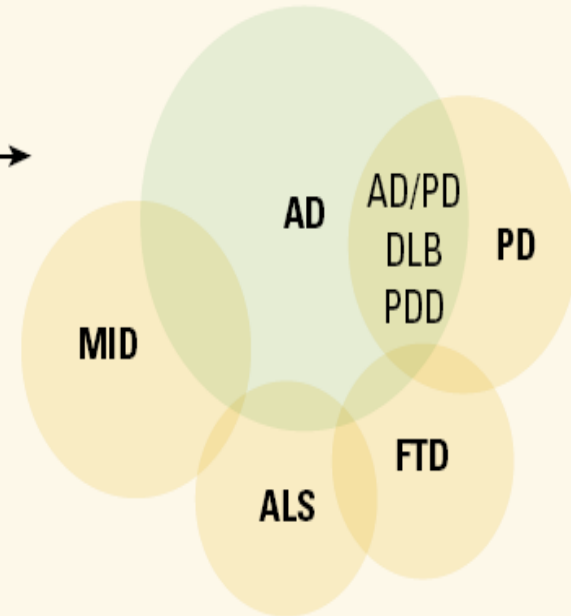
Damaging Processes Occurring Before Symptoms Appear

Amyloid plaques
Synuclein deposits
Tau tangles
Other abnormal protein deposits
Nutritional compromise
Hormonal changes
Reduced oxygen flow to tissues
Toxic processes

Early Symptoms

Tremor
Memory loss
Executive function problems
Movement problems
Gait and balance problems
Sleep-wake disorders
Hallucinations
Delusions
Rigidity

Neurodegenerative Diseases*

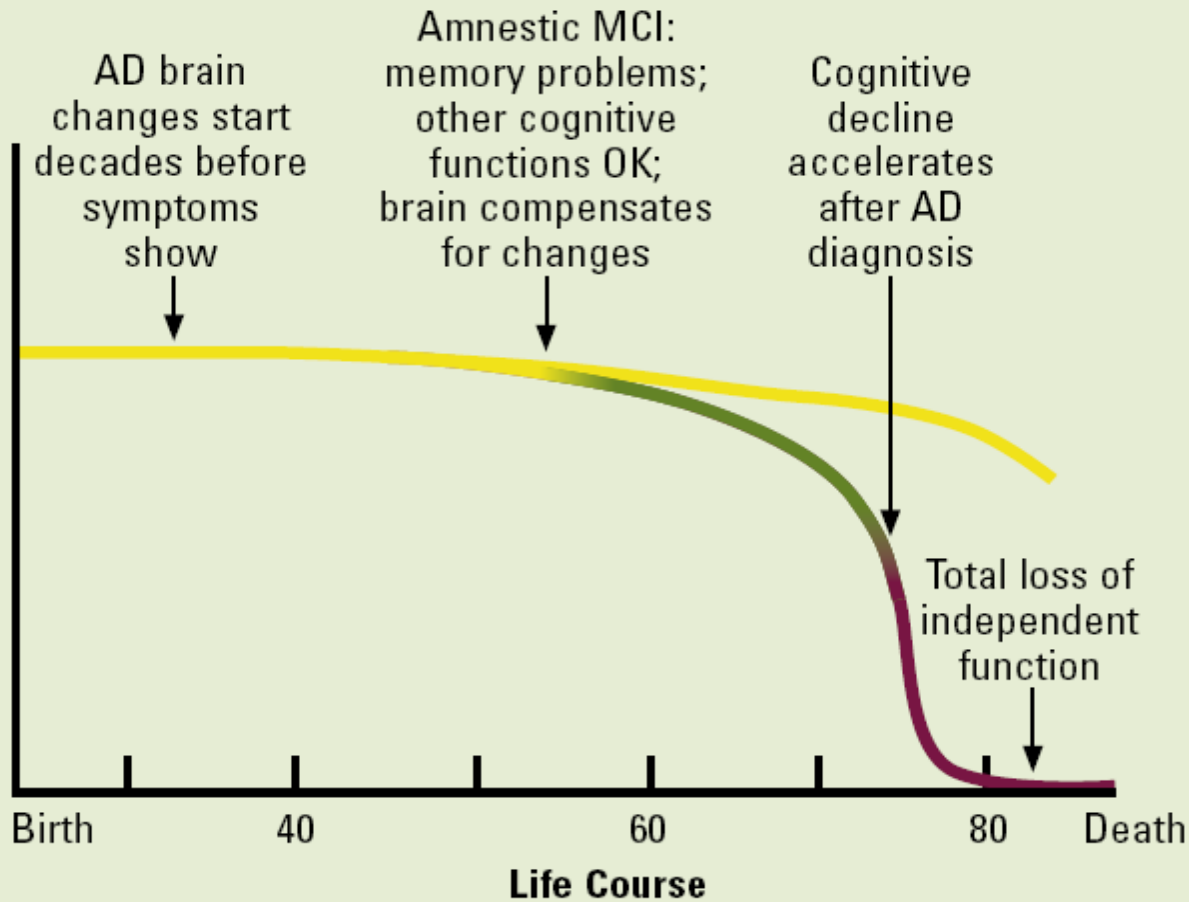


*AD = Alzheimer's disease, AD/PD = AD with parkinsonism, ALS = amyotrophic lateral sclerosis, DLB = dementia with Lewy bodies, FTD = frontotemporal dementia, MID = multi-infarct dementia (also known as vascular dementia), PD = Parkinson's disease, PDD = Parkinson's disease with dementia

Adapted from an Emory University illustration

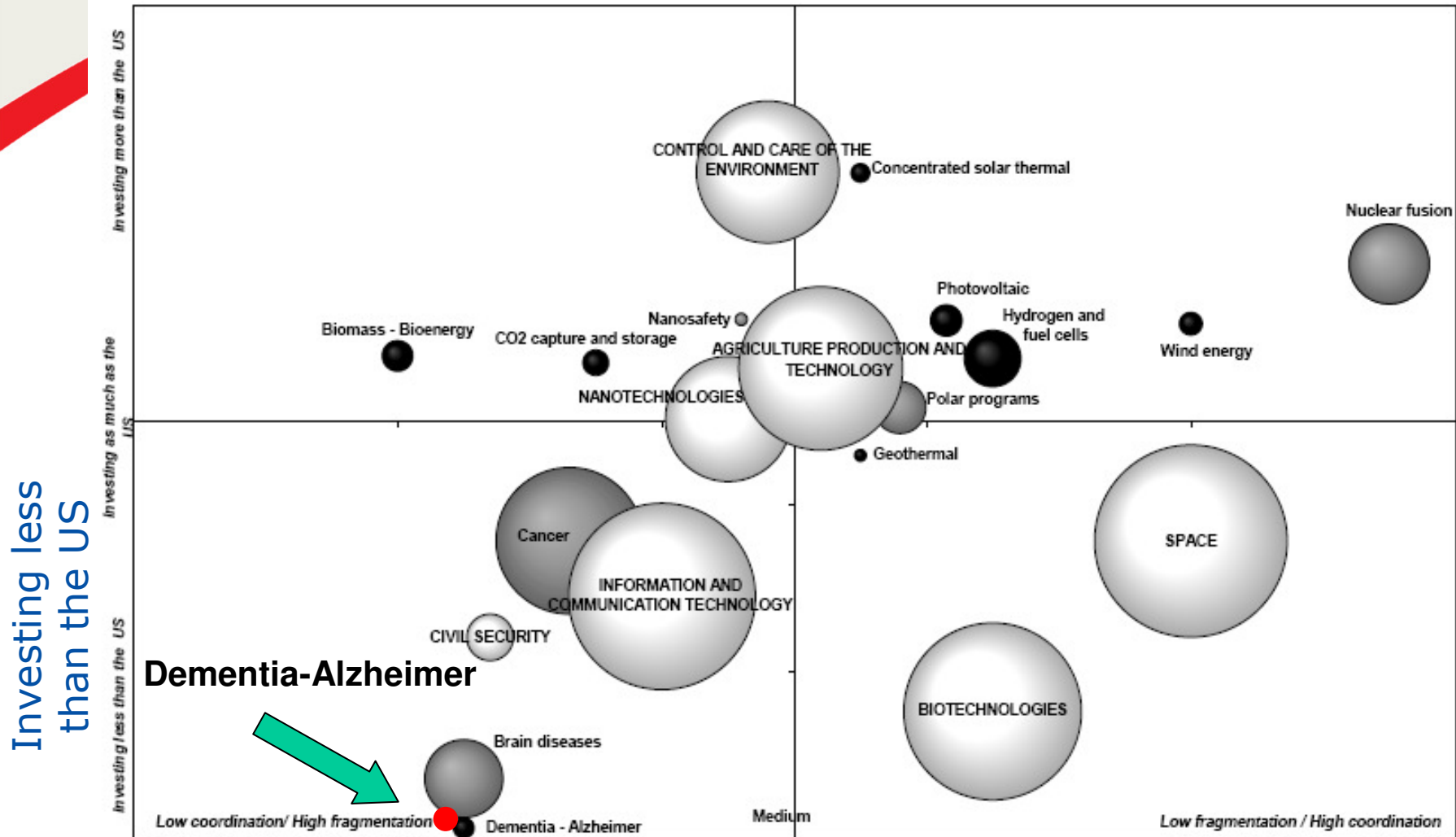
A substantial research effort is needed

➔ We must intervene earlier in the process



Healthy Aging Amnestic MCI Clinically Diagnosed AD

A substantial research effort is needed



Investing less than the US

Dementia-Alzheimer

Low coordination / High fragmentation

Towards joint programming in research Working together to tackle common challenges more effectively, EU COM (2008) 468





EUROPEAN
COMMISSION

European
Research Area

Why the focus on neurodegenerative diseases, in particular Alzheimer's disease?



A major issue for Public health in Europe



A field of growing priority for research funding in Europe



A substantial research effort is needed



The benefits of better coordination



The benefits of better coordination



In spite of national and EU research efforts in this field, the picture is complex due to the variety of financing systems, research policies and organisation structures across Member States



Compartmentalisation between disciplines and poor linkages between basic, clinical, public health research and social sciences hampers translation of knowledge into clinical practice and care delivery; the national context reinforces also fragmentation



Coordinating national efforts will allow a critical mass of skills, knowledge and resources to be pooled and to jointly address the medical and social challenges posed by these diseases



EUROPEAN
COMMISSION

European
Research Area

How to implement the European pilot initiative to combat neurodegenerative diseases, in particular Alzheimer's ?



A case for Joint programming



State of play of the initiative



A case for Joint Programming

Joint programming (JP)

- Commission Communication on Joint Programming in July 2008
- Council Conclusions on Pilot JP in AD in December 2008
- Commission Proposal for Council Recommendation in July 2009
COM(2009) 379 final

Definition:

Member States engage **voluntarily** and on the basis of **variable geometry**

... in the definition, development and implementation of **common strategic research agendas**

... based on a **common vision** on how to address **major societal challenges**



A case for Joint Programming

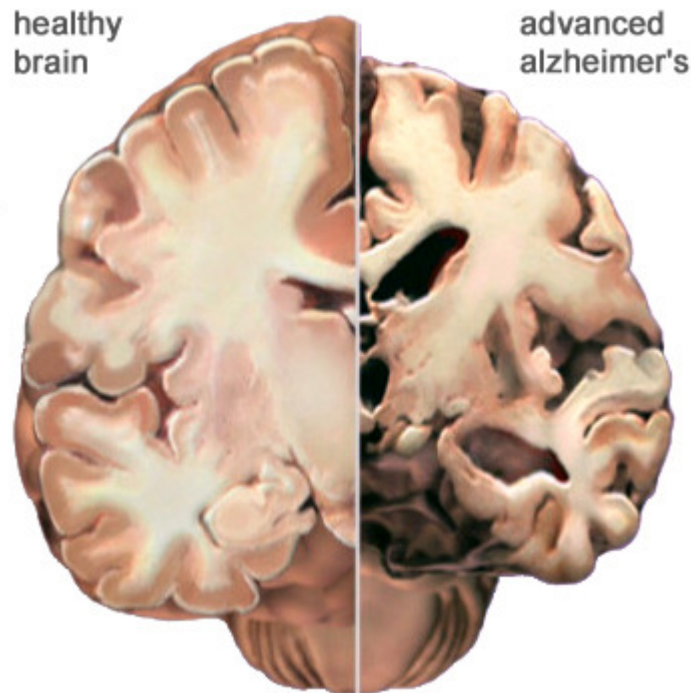
- Maximise value of national investments in research on AD via coordinated mobilisation of the largest possible number of MS.
- Strengthen coordination of national research efforts in this field at European level.
- Reduce barriers between disciplines and fields of research and compartmentalisation of research activities.
- Reinforce links between basic, clinical, public health research and social sciences.
- Accelerate the integration of basic knowledge into current clinical practice, care organisation and delivery.



EUROPEAN
COMMISSION

European
Research Area

A case for Joint Programming



- Assess effectiveness of existing treatments and develop new ones through large scale studies
- Develop tests for early diagnosis
- Address risk factors through large cross-borders population studies taking advantage of the European diversity
- Establish databases and registries
- Standardise diagnostic criteria and assessment tools throughout Member States
- Share knowledge on health care systems





EUROPEAN
COMMISSION

European
Research Area

How to implement the European pilot initiative to combat neurodegenerative diseases, in particular Alzheimer's ?



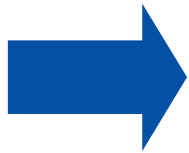
A case for Joint programming



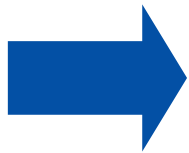
State of play of the initiative



State of play of the initiative

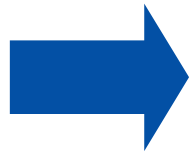


September and December 2008: EU Council of Ministers acknowledged the challenges posed by neurodegenerative diseases and concluded on the need to launch an encompassing European initiative by Member States, the European Commission and stakeholders with a view to combatting neurodegenerative diseases

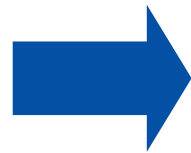


There was agreement that Joint Programming would be an appropriate tool for the implementation of such an initiative

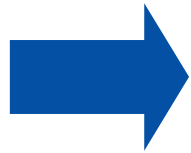
State of play of the initiative



The EC Proposal for a Council Recommendation on ND was presented at the Competitiveness Council on 25 Sep and at EP / ITRE on 29 Sep 2009



Opinion currently being sought by European Parliament, Economic and Social Committee, Committee of the Regions



Adoption by Council planned for 3 Dec 2009

State of play of the initiative



Some 20 countries* are currently setting up the modalities for the establishment of a governance model and the implementation structure for this initiative, 2nd MB meeting 6 Oct, next on 13 Nov



The Commission will contribute to it by providing, as from 2010, a financial and legal framework – in the form of a coordination action - to support Member States during the implementation phase and in the definition of the Strategic Research Agenda (Call HEALTH-2010.4.2-8, deadline 19 Nov 2009)



This initiative will also complement Community efforts undertaken in the framework of the recently launched “European Initiative on Alzheimer’s and other dementias”, COM(2009) 380 final

* BE, CZ, DE, DK, ES, FI, FR, GR, HU, IE, IT, LU, NL, PL, SE, SK, UK, CH, NO, TR



EUROPEAN
COMMISSION

European
Research Area

THANK YOU FOR YOUR ATTENTION

Questions?

Manuel Hallen, MD
Head of Unit 'Medical & Public Health Research'
DG RTD, European Commission

