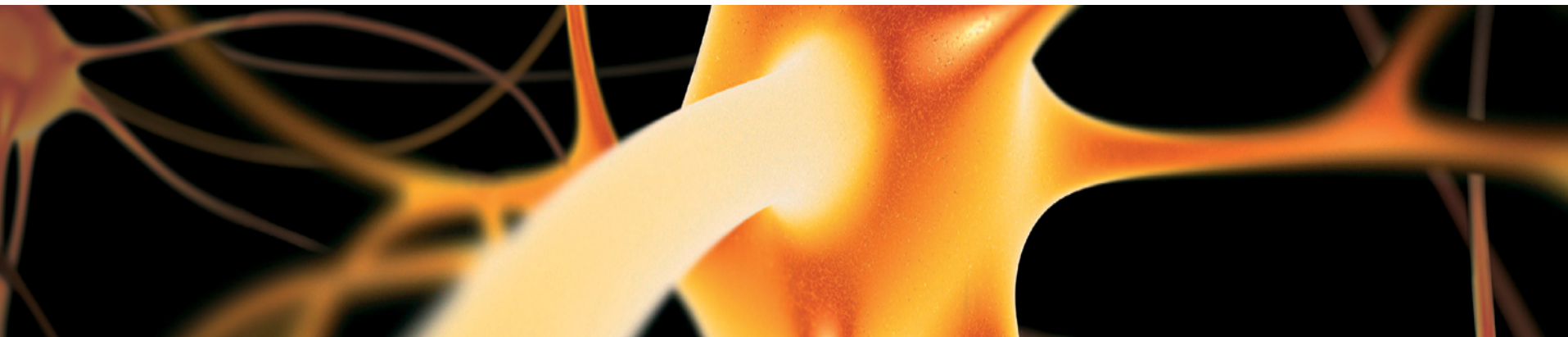


# **“Joint Programming”**

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



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

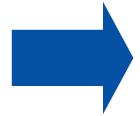
A global challenge:



7.3 million Europeans suffer from Alzheimer's disease and other forms of dementia

The total cost of dementia in Europe in 2005 was in the order of € 55 billion

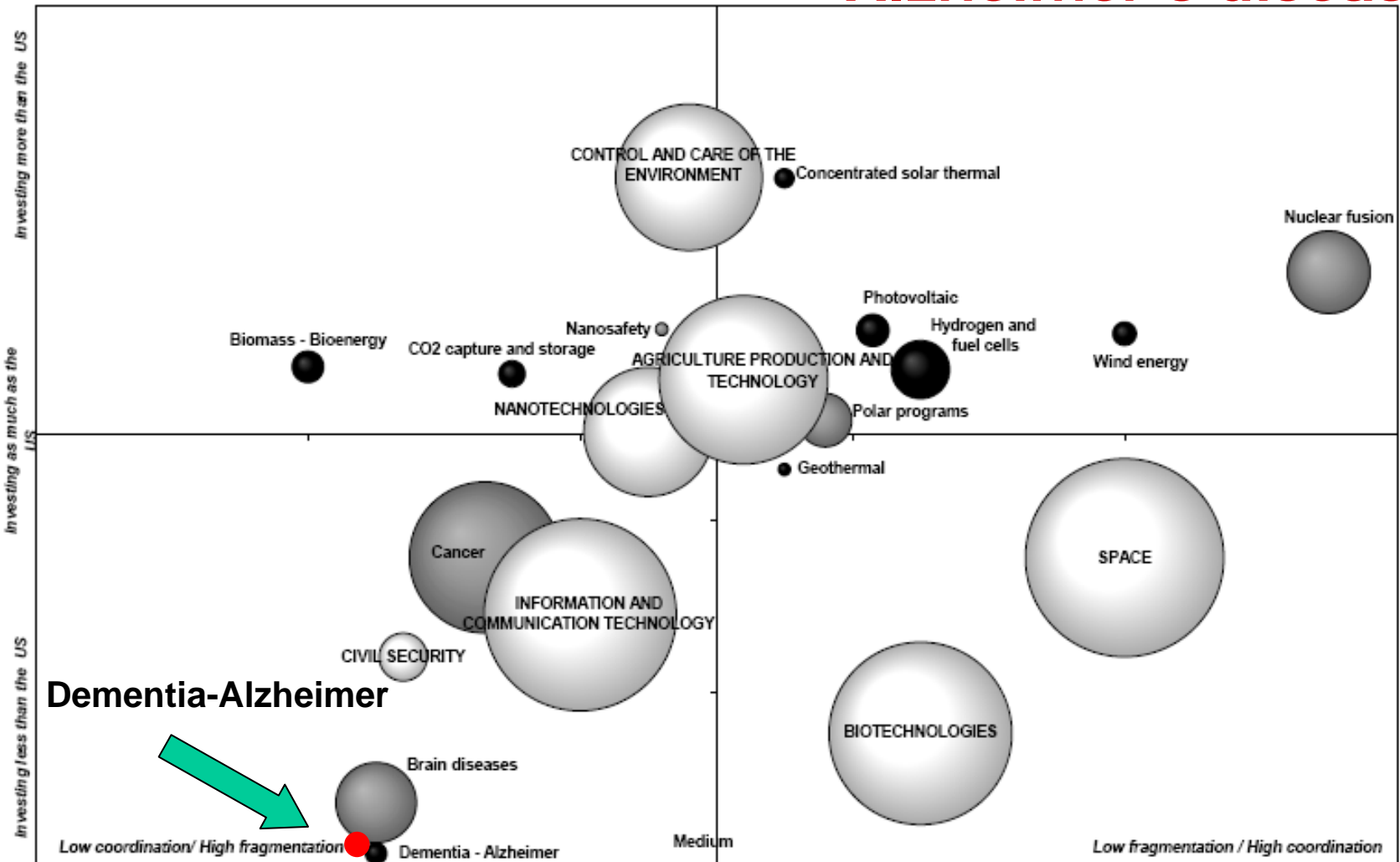
And it will get worse:



Over 11 million Europeans will suffer from Alzheimer's disease and other forms of dementia by 2040

# Why the focus on research into neurodegenerative diseases, Alzheimer's disease?

Investing less than the US



Low coordination / High fragmentation

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

# “Joint Programming” a European pilot initiative for combating neurodegenerative diseases

## Joint programming

Commission Communication on Joint Programming in July 2008  
and Council Conclusions adopted in December 2008 – Council  
Recommendations expected end 2009

### 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**

# “Joint Programming” a European pilot initiative for combating neurodegenerative diseases

## Benefits

- Added-value and benefits to be expected from this initiative
- Increase of value of national investments in research on AD+ via JP via coordinated mobilisation of the largest possible number of MS
- Coordination of national research efforts in this field at European level is still to be achieved
- Key elements accountable for this situation include:
  - barriers between disciplines and fields of research, and the compartmentalisation of research activities.
  - major weakness: missing link between basic, clinical and social research,
  - limited integration of the existing or acquired basic knowledge into current clinical practice and care organisation and delivery.

# Research needs in neurodegenerative diseases and Alzheimer's

## Basic

- Research on genetic susceptibility and genome-wide association studies (GWAS)
- 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 tissues
- 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

## Health and Social Services

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

# “Joint Programming” a European pilot initiative for combating neurodegenerative diseases

## Considerations

- Reaching consensus and building agreement
- EU Member States joining forces and to combine research capacities and financial resources
- Voluntary commitment of Member States
- Variable geometry approach – minimalist versus maximalist approach
- JP-ND initiative – a pilot, a model for the future
- Governance structure – Member State representatives - management board – terms of reference – strategic discussions ...