



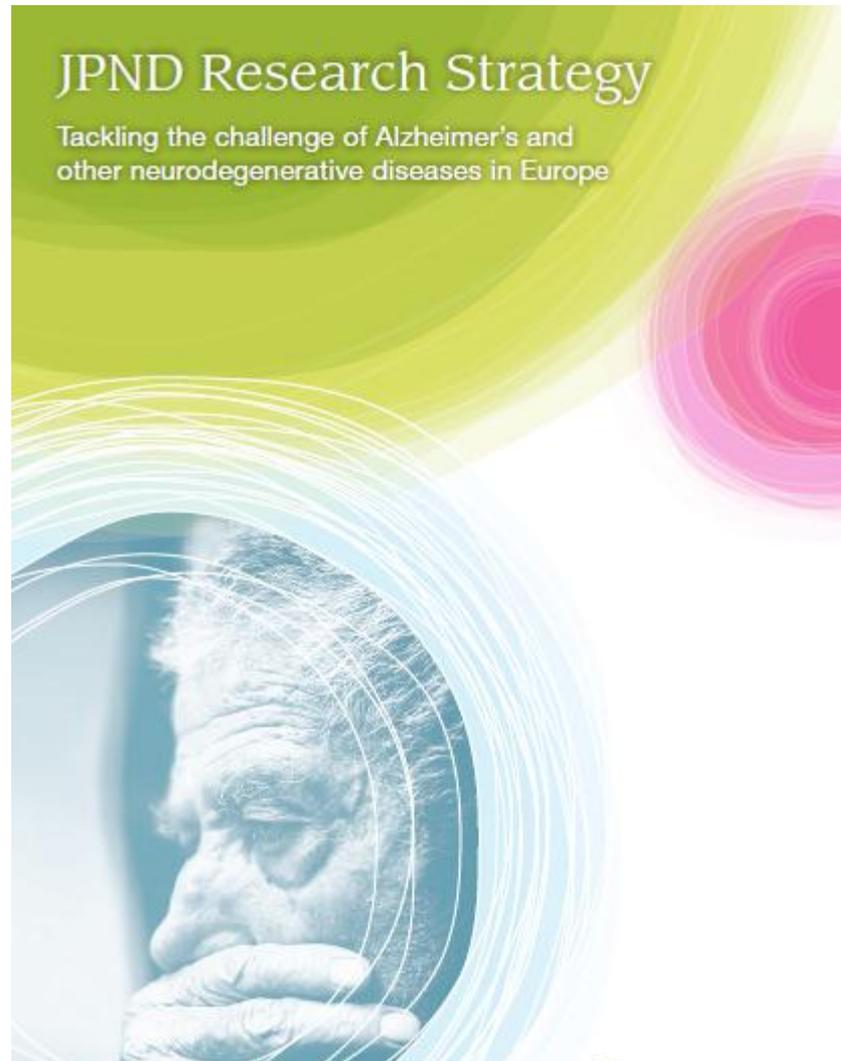
**JPND**  
research

EU Joint Programme – Neurodegenerative Disease Research

# JPND Research Strategy

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**Chair, JPND Scientific Advisory Board**

# JPND Research Strategy



# Scientific Advisory Board



# Delivering the Research Strategy

- 1. Mapping exercise**  
Scoping existing research spend and infrastructure (academic)
- 2. Thematic workshops (academia)**  
Basic, Clinical and Healthcare themes
- 3. Stakeholder meetings**  
Industry, charities, funders, policy makers  
Patient and carer associations, health care professionals
- 4. Integrating workshop**  
SAB and opinion leaders from thematic and stakeholder workshops
- 5. Consultation**  
Public online consultation



# What about stakeholders?

## Key stakeholder groups for JPND

- Patients and Carers
- Research charities and other funders
- Healthcare professionals
- Policy makers
- Industry:
  - biopharma, biotech, diagnostics and devices
  - informatics, telemedicine, smart home technologies



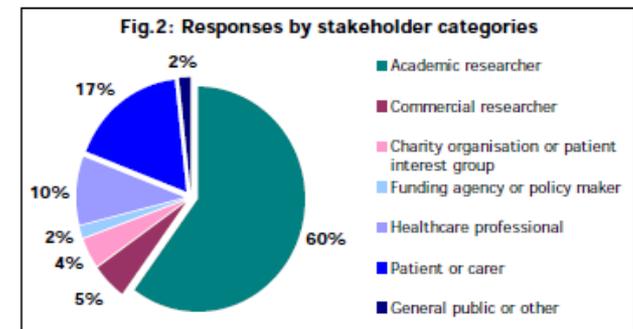
# Available on JPND Website

- <http://www.neurodegenerationresearch.eu>
- <http://www.jpnd.eu>

- Full Research Strategy
- Executive Summary in 14 Languages
- Reports summarising responses received from consultations



The screenshot shows the JPND Research Strategy website. The header includes the JPND logo and navigation links: Home, About, Initiatives, Search our Database, News & Events, Press & Media, and Contact. The main content area features the title "JPND Research Strategy" and the subtitle "Tackling the challenge of Alzheimer's and other neurodegenerative diseases in Europe". Below this, there is a section for "Türkçe çevirisi" (Turkish translation) and a "Latest News" section with a link to "Results from JPND Transnational Biomarkers Call" dated 9 December 2011. The sidebar contains information about the JPND initiative, the launch of the European Research Strategy in February 2012, and a joint transnational call for biomarkers research.



The largest group of respondents, academic researchers, came from the following research domains: basic 54%, clinical 32% or socio-economic/healthcare 14% (see Fig 3 below):

# Scope of the initiative

## Focus on Three Domains

### Scientific

- Animal models
- Biobanks
- Cohorts/registries
- Disease pathology

### Medical

- Early diagnosis
- Prevention
- Clinical trials

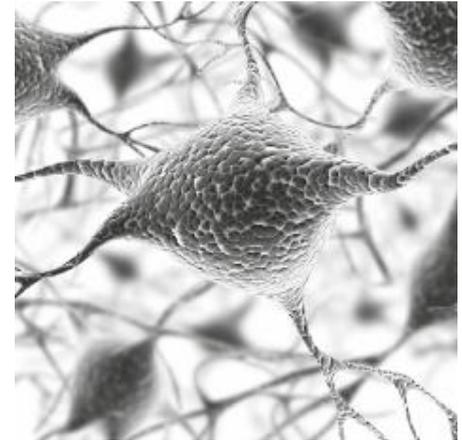
### Social

- Health care delivery
- Home automation
- Health economics
- Ethics



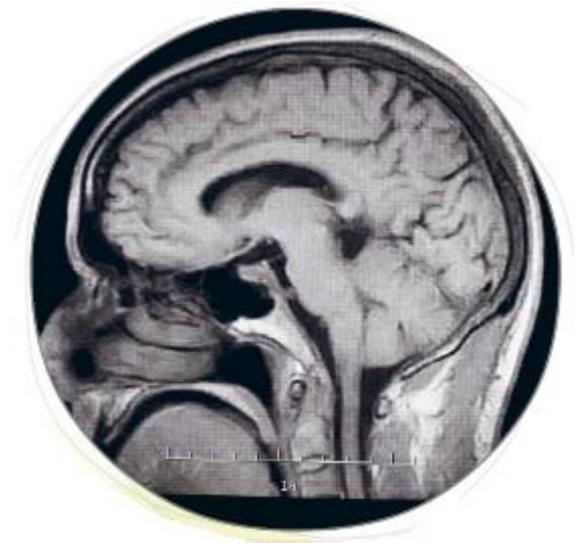
# Scientific Priorities: Origins of neurodegenerative disease

- Further knowledge is needed regarding:
  - Causes of specific ND
  - Factors that determine people's risk and resilience
  - Triggering events leading to illness
  - Ageing process
- Characterise 'at-risk' populations;  
genetic, epigenetic and environmental risk factors
- Identify environmental and behavioural modulators



# Scientific Priorities: Disease mechanisms and models

- **Increase understanding of underlying disease mechanisms to:**
  - Underpin the development of new diagnostic and therapeutic approaches
  - Identify appropriate time-windows for intervention
  - Establish novel cell-based and animal models
  - Elucidate the biological and environmental basis of behavioural and psychological symptoms in ND



# Scientific Priorities: Disease definitions and diagnosis

- Refine and update current diagnostic criteria
- Better define the various forms and subtypes of ND, including the stages **before** clinical symptoms emerge
- Provide new/improved diagnostic tools for earlier detection
- Establish new biomarkers to:
  - Provide links between human and animal-based studies
  - Provide measures of disease progression, prognosis and treatment effects
- Standardise and harmonise tools and assessments to ensure comparability of results and support cross-centre studies



# Scientific Priorities: Treatments and prevention

- Promoting connectivity between studies in animal/cell models and patients
- Improve selection (or stratification) of subjects entering clinical trials
- Further develop psychosocial interventions, paying attention to the promotion of social inclusion and carer involvement
- Establish cohorts of patients with preclinical ND to provide a platform for the future testing of interventions to prevent or slow disease
- Pursue longer-term approaches that promote regenerative strategies and develop novel systems for the delivery and targeting of therapeutics to specific sites in the brain and nervous system



# Scientific Priorities: Healthcare and social care

- Evaluate equity of access to, and cost-effectiveness of, pathways to diagnosis, treatment, care & support
- Identify factors impacting on disability and health-related QoL in ND, including comorbidity, nutrition, and interaction with family, carers, environment, and health/social care systems
- Relate short-term studies to real-world settings
- Improve outcome measures to better reflect patient & carer perspectives
- Addressing specific burden of ND in strategies for assisted living
- Research in palliative and end-of-life care



# Enabling Activities

- Knowing our research capability
  - European and National ND research activity mapped
- Supportive infrastructure and platforms
  - integration and harmonisation of data and materials
  - standardisation of guidelines, methods and tools for data collection and analysis
  - review policy frameworks to facilitate research across the full range of healthcare structures
- Working in partnership with industry
  - Promote connection between and across academic and commercial domains
  - Encourage data and resource exchange



# Enabling Activities

- Working with regulatory organisations
  - Effective translation of research through to patient benefit
  - Ensure that regulation is easily understood + proportionate to risk
  - Promote regulatory support networks
- International partnership beyond Europe
  - Unmet clinical need and societal impact of ND is a global issue
  - Cooperation should be strategic and offer clear added value
- Capacity building
  - Networks across and between different disciplines
  - Methodological hubs



# Enabling Activities

- Education and Training
  - advice given to patients should be based upon;
    - a good understanding of the disorder
    - the patient needs characteristic of these conditions
    - the available evidence-based options for treatment
  - tailored clinical and research education and training programmes
  - public health messaging
- Connection to policy makers
  - a framework to highlight issues for national policy consideration, and promote compatibility between countries
  - address translational gaps in policy
- Communication and outreach
  - promote translation into policy and practice
  - ensure stakeholder communities are informed



# Summary

- Strategy sets out the common vision of the 25 European countries involved
- Provides a strategic approach to support world-class research that can;
  - exploit emerging scientific opportunities
  - confront barriers to progress
  - provide new approaches to prevention, intervention and care.
- Addresses the full spectrum of research and approaches that are required to achieve impact
- Important role of stakeholder groups to deliver the agenda

