Joint Programming in Neurodegenerative Disease Research (JPND)

Building Alliances and Collaborations

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Disclosure

- CEO of Fondation Plan Alzheimer
- Conference for Servier
- Consultancies for Takeda, Total
- Member of Alzprotect SAB
- Co-funder of Genoscreen
Dementia prevalence estimates, 2010

From Wimo A et al, Alzheimer’s & Dementia, 2017
Dementia prevalence estimates, 2015

From Wimo A et al, Alzheimer’s & Dementia, 2017
Subcategory costs of dementia, 2010

From Wimo A et al, Alzheimer’s & Dementia, 2017
Subcategory costs of dementia, 2015

US$ (bn)

$818 billion

2015

Direct medical costs
Direct social sector costs
Informal care costs

From Wimo A et al, Alzheimer’s & Dementia, 2017
Forecasted global costs of dementia 2015-2030

From Wimo A et al, Alzheimer’s & Dementia, 2017
Major societal “Grand Challenges”

- Energy
- Climate Change
- Food & Health
- Neurodegeneration
Overcoming barriers in Europe

- Fragmented Research
- Non-concerted National Funding
- Duplication
- < 5% of total EU countries research budget shared (mainly through the European Commission)
Joint programming was originally created as a Member States-led initiative in Europe. It aims to address “grand challenges” to EU and global society by coordinating national research programmes to increase the impact and effectiveness of research efforts.

Source: Communication from the Commission to the European Parliament, the Council, the European Economic and social committee and the Committee of the Regions toward Joint Programming in Research: Working together to tackle common challenges more effectively - COM(2008) 468 final, Brussels
Three pillars

- **Shared vision**: JPND countries engage voluntarily and on a variable-geometry basis to tackle the major societal challenge of neurodegenerative diseases

- **Reactive management structure**: to address as efficiently as possible this societal challenge

- **Common strategic research and innovation agenda**: developed and implemented by all JPND countries and is the basis for alignment of national research programs
Overcoming barriers

**New forms of long-term collaboration** between local, regional, national and European policy makers and actors that reduce fragmentation and increase the impact of national RD&I investments

Fostering and testing **innovative approaches and science-policy cooperation**

**Gateways for scientific excellence, relevance and international cooperation**

**Strategic platforms for alignment** in the broader sense, using different instruments and other innovative approaches to achieve their strategic goals, in conjunction with the Commission's tools.
What are the goals of JPND?

To tackle the challenge of Alzheimer’s and other neurodegenerative diseases, the JPND Research Strategy sets the following goals:

• To develop new treatments and preventive strategies
• To improve health and social care approaches
• To raise awareness and de-stigmatise neurodegenerative disorders
• To alleviate the economic and social burden of these diseases
JPND brings together

- Researchers (Basic, Clinical, Healthcare/Social)
- National Funding Bodies
- National Research Strategies and Investments
- Industry
Scope of the JPND initiative

Disease areas

Alzheimer's disease and other dementias
Huntington's disease
Motor Neurone Diseases
Parkinson's disease and PD-related disorders
Prion disease
Spinal muscular atrophy (SMA)
Spinocerebellar ataxia (SCA)

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

Medical
- Early diagnosis
- Prevention
- Clinical trials

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

Focus on Three Domains
Overcoming barriers in Europe and beyond

JPND is the largest global ND research initiative led by EU countries, with 30 participating

EU member states

Associated countries

Partner countries

In progress

India
United States
South Korea
China
LAC countries
Japan

Albania
Australia
Austria
Belgium
Bulgaria
Canada
Croatia
Czech Republic
Denmark
Finland
France
Germany
Greece
Hungary
Ireland
Israel
Italy
Luxembourg
Netherlands
Norway
Poland
Portugal
Romania
Slovakia
Slovenia
Spain
Sweden
Switzerland
Turkey
United Kingdom
JPND progress to date

- SRIA for a Common European/Global Strategy
- Mapping exercise
- Alignment of national plans and strategies
- Phase I Implementation (2012-2014)
  - Joint Transnational Calls
  - Alignment Actions
- Operating plan (2015-2020)
- Widening participation
- Internationalisation
- Stakeholder involvement
- Monitoring and assessment activities
- Communication and dissemination
Implementing transnational and additional joint calls

Total investment €128 M

Joint Transnational Calls:
- Between 20 and 175 proposals
- Between 122 and 892 teams
- 95 projects supported + ongoing €23 million call
- Including 24 projects in the Center of Excellence Network program
JPND JTC number of proposals

- Harmonisation of...
- Health Care
- Risk factors
- Preventive strategies
- Cross disease analysis
- Cohort WG
- Cofund
- 2015

Number of proposals:
- 14
- 22
- 52
- 35
- 92
- 22
- 175
From basic and translational research...

- June 1, 2012–May 31, 2015
- 52 partners from 21 countries
- Standardized the sampling and measurement for the biomarkers across most centers in Europe
- 135 publ in peer reviewed journals
- Laboratory training & certification
- Identification of two new biomarkers
- The work will continue in a European “CSF Society” established by the members of BIOMARKAPD.
... to social and healthcare research

The Meeting Centres Support Programme is an innovative, person-centred approach for community dwelling people with dementia and their family carers that was originally developed in the Netherlands, where it has been successfully implemented at 118 locations.

The MEETINGDEM project aims to implement and then evaluate this Dutch programme in three additional European countries: Italy, Poland and the United Kingdom.

**Total Funding:** €1.2 million  
**Start Date:** January, 2014  
**Duration:** 3 years  
**Coordinator:** Rose-Marie Dröes
JPND Alignment Actions, working together

- Alignment of National Strategies
- Alignment of National Activities
- Industry Partnership
- Assisted Living Technologies
- Longitudinal Cohorts
- Animal and Cell Models
- Palliative Care
- Patient + Public Involvement
- Optimisation of biomarkers
Big Data for Advancing Dementia Research

Ulrike Deetjen | Eric T. Meyer | Ralph Schroeder

Oxford Internet Institute, University of Oxford

March 2015

OECD: Elettra Ronchi, Christian Reimsbach-Kounatze

OECD International Advisory Group: Robin Buckle (Chair), Philippe Amouyel, Neil Buckholtz, Giovanni Frisoni, Yves Joanette, Richard Johnson, Miia Kivipelto, Martin Rossor, Donald Stuss, Yoshiaki Tojo (see Appendix for affiliations)

All interviewees represent their own personal views and not necessarily the official standpoint of any organisation. This report should not be reported as representing the official views of the OECD or of its member countries.


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The Challenges of Big Data

- Need to harness big data to help develop a cure and test new care models.
- Both **broad** (population health and health care) and **deep** (clinical and biological) data are needed.
Why cohorts? Linking and comparing longitudinal cohort studies could lead to important insights and statistically more powerful conclusions about ND. But researchers face hurdles:

- Information on cohort studies is often difficult to find
- Identifying and connecting with the right contacts from each cohort can be challenging

Main objective: to facilitate information exchange, greater use of cohorts and new collaborations to help promote:

- A larger volume of ND research
- Increased efficiency
- Greater scientific impact

More info: cohorts@jpnd.eu
How does the JPND Global Cohort Portal work?

Search the database

Choose how your results display

Obtain high-level overview and cohort contacts
Stakeholder Groups in JPND

Actions aimed at multiple levels within 9 identified stakeholder groups
Stakeholder Engagement in JPND

• **Patient and Public Involvement (PPI) Advisory Board**
  ✓ Makes visible the perspectives of patients, their relatives, and their caregivers and provides rapid and frank feedback and early advice

• **Communications network to engage the community of JPND stakeholders**
  ✓ Engage in a continuous, two-way relationship to advise, support and work together with stakeholders (e.g., Eurocarers, the European Brain Council).
  ✓ Collaborate closely with patient and caregiver organisations (e.g., Alzheimer Europe, EPDA) to develop and disseminate content that will optimally facilitate knowledge transfer

• **Ensure awareness of the importance of JPND among policy-making stakeholders at the European and national levels**
International Stakeholders
Active Social Media Conversation

- Twitter
- YouTube
- Flickr
- SlideShare
How can countries connect with JPND?

- Members of JPND benefit from an overview of coordinated activity between 30 countries, accessible through one entry point, as well as opportunities to shape harmonised global approaches for both research and policy.

- Engagement may include:
  - Interactions with a JPND body (e.g., Scientific Advisory Board or Management Board) to further JPND’s understanding of a country’s research strategy, strengths and resources and to identify where there may be potential for new links and knowledge sharing
  - Participation in a JPND conference
  - Scientific participation in JPND Working Groups
  - Contribution to one or more future JPND funding calls
  - Full participation and membership
Can we change the trajectory?

Yes, if we work together
Keep up to date

- Visit the JPND website:
  - http://www.jpnd.eu

- Sign up to the JPND News Feeds

- E-mail us: secretariat@jpnd.eu

@JPNDEurope