Joint Programming in Neurodegenerative Disease Research

Coordinating approaches to research across Europe and over

Prof. Philippe Amouyel, MD, PhD
JPND Chair
Madrid, October 22nd, 2014
Neurodegenerative diseases in Europe

A major societal challenge for the coming years
Research efforts are fragmented

Size of sphere proportional to funding
A European Mobilization

- Informal meeting on competitiveness for Ministers of Research, Versailles, 17th July 2008
- Chaired by the French Minister of Higher Education and Research, Mrs Valérie Pécresse

“to put the issue of neurodegenerative diseases in the top priorities of the agenda of the European Council.”

“to launch a joint programme of research on these diseases, combining socio-economic and medico-biological issues.”
What is Joint Programming?

A Member States-led initiative in Europe which aims to address “grand challenges” to EU society by coordinating national research programmes within the EU 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
Joint Programming - a definition

Three pillars

- A shared vision: European countries engaging voluntarily and on a variable geometry basis to tackle a major societal challenge

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

- A common strategic research agenda: to be defined, developed and implemented
Major societal "Grand Challenges"

- Energy
- Climate Change
- Food & Health
- Neurodegeneration
A Shared Vision
Declaration of Intent

- Announcement on December 2\textsuperscript{nd}, 2008
- Interest and emergency recognized for joint action with a consensus focus on Alzheimer’s disease
- Focusing on the actions for which the European dimension has added value compared to respective national actions
- Defining the topics of a joint program that could be implemented quickly
- 10 countries: France, UK, Ireland, Italy, Sweden, Denmark, Spain, The Netherlands, Czech Republic, Switzerland (+ Finland)
We cannot tackle neurodegenerative diseases by acting as single countries.

JPND is a global research initiative led by EU countries, with 28 participating EU member states, Associated countries, and Third countries.

Increasing coordination of national research programmes to improve impact and effectiveness.
JPND brings together:

- Researchers (Basic, Clinical, Healthcare/Social)
- National Funding Bodies
- National Research Strategies and Investments
Current JPND strategy

*To increase coordinated investment in ND research aimed at finding causes of disease, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases*

- **Immediate JPND goals:**
  - To add value to national investments through coordinated action
  - To encourage the development of national research strategies in ND
  - To engage in partnership to reach the full potential of JPND
A Management Structure
Organisation

Management Board
- 28 countries represented
- Members mandated to act
- Secretariat Delphine Smagghe
- Chair Philippe Amouyel - France

Executive Board
- Vice-Chair Adriana Maggi - Italy
- Robin Buckle - UK
- Mogens Horder - Denmark
- Marlies Dorlochter - Germany

Steering Committee
Executive Board +
- Derick Mitchel - Ireland
- Rainer Girgenrath - Germany
- Edvard Beem - Netherlands

Scientific Advisory Board
- 18 Members, chosen for scientific excellence and competence

JPND currently partly supported by FP7-JUMPAHEAD until August 2014 (GA. 260774)
DEFRAGMENTATION
- WHAT JPND IS ALL ABOUT

STRATEGIC RESEARCH AGENDA

ALIGNMENT OF EU COUNTRIES
ON COMMON RESEARCH GOALS
To tackle the challenge of Alzheimer’s and other neurodegenerative diseases, the goals of the JPND Research Strategy are:

- *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*
Scope of the JPND initiative

Disease areas that the JPND Scientific Advisory Board has included:

- 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)

Disease areas that the JPND Scientific Advisory Board have excluded:

- Multiple sclerosis
- Age-related macular degeneration
- Conditions where the primary lesion is not neurodegenerative
- Loss of function or cell death due directly to cancer, oedema, haemorrhage, trauma, poisoning and hypoxia
- Comorbid conditions
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
Agreed by 25 Member States + Associated Countries

• Officially Launched Feb 7th 2012

Thematic priorities for future research:

• The origins of neurodegenerative disease
• Disease mechanisms and models
• Disease definitions and diagnosis
• Developing therapies, preventive strategies and interventions
• Healthcare and social care
JPND Research Strategy (SRA)

- **Enabling activities for future research:**
  - Knowing our research capability
  - Supportive infrastructure and platforms
  - Working in partnership with industry
  - Working with regulatory organisations
  - International partnership beyond Europe
  - Capacity building
  - Education and Training
  - Connection to policy makers
  - Communication and outreach
How can JPND reach its goals?

• Alignment of research in Member Countries
• Partnership with the European Commission
• Partnership with Industry
• Partnership with other international organisations
• Involvement of Patients and Public
Strategic Alignment

Phase I SRA Implementation (2012-2014)

- **JPND-level**
  - Alignment Actions / Action Groups
  - Annual Transnational Calls for Proposals

- **Member country-level**
  - National Plans and Strategies

- **ERA-Level**
  - Synergy between JPND actions and H2020 programme
Alignment Actions / Action Groups

• To determine transnational research needs and opportunities
  • Palliative Care (chair: E. Connolly)
  • Animal and Cell Models (chair: A. Maggi)
  • Assisted Living Technologies (chair: J. Hoogendam)
  • Longitudinal Cohort Studies (chair: R. Buckle)

• To promote engagement, commitment and partnerships
  • Engagement, partnership with EC + non-EU countries (chair: P. Amouyel)
  • Engagement and Partnership with Industry (chair: A. Maggi)
  • User and Public Involvement in ND Research (chair: M. Horder)
  • Linkage + Alignment of National Plans and Initiatives (chair: E. Hirsch)
Action Group Recommendations

LONGITUDINAL COHORT STUDIES IN NEURODEGENERATIVE RESEARCH

Report of the JPND Action Group

September 2013

EXPERIMENTAL MODELS FOR NEURODEGENERATIVE DISEASES

Report of the JPND Action Group

January 2014

JPND research
# SRA Implementation (2012-2014)

## Annual Calls for Proposals

<table>
<thead>
<tr>
<th>Year</th>
<th>Total fund available</th>
<th>Research Area</th>
<th>No. of Projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>€16M</td>
<td>Optimization of biomarkers + harmonization of their use</td>
<td>4</td>
</tr>
<tr>
<td>2012</td>
<td>€18M</td>
<td>Risk and Protective Factors</td>
<td>5</td>
</tr>
<tr>
<td>2012</td>
<td>€11M</td>
<td>Evaluation of Healthcare</td>
<td>6</td>
</tr>
<tr>
<td>2013</td>
<td>€12M</td>
<td>Cross-Disease Analysis</td>
<td>TBC</td>
</tr>
<tr>
<td>2013</td>
<td>€11M</td>
<td>Preventive Strategies</td>
<td>TBC</td>
</tr>
</tbody>
</table>

## Centres of Excellence in Neurodegeneration (CoEN)

<table>
<thead>
<tr>
<th>Year</th>
<th>Total fund available</th>
<th>Research Area</th>
<th>No. of Projects</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>€6M</td>
<td>Phase I : common resources and methodological approaches</td>
<td>8</td>
</tr>
<tr>
<td>2012-13</td>
<td>€8M</td>
<td>Phase II : “Pathfinder” projects</td>
<td>5</td>
</tr>
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</table>
# Call statistics

<table>
<thead>
<tr>
<th>Year</th>
<th>Call area of interest</th>
<th>No. of proposals submitted</th>
<th>Budget requested (million €)</th>
<th>No. of proposals recommended for funding</th>
<th>No. of proposals supported</th>
<th>Budget supported (million €)</th>
<th>Success rate (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2011</td>
<td>Harmonization of Biomarkers</td>
<td>14</td>
<td>€31</td>
<td>5</td>
<td>4</td>
<td>€14</td>
<td>29%</td>
</tr>
<tr>
<td>2012</td>
<td>Risk and Protective Factors</td>
<td>52</td>
<td>€97</td>
<td>18</td>
<td>5</td>
<td>€17</td>
<td>10%</td>
</tr>
<tr>
<td>2012</td>
<td>Healthcare Evaluation</td>
<td>22</td>
<td>€29</td>
<td>9</td>
<td>6</td>
<td>€9</td>
<td>27%</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td></td>
<td><strong>88</strong></td>
<td><strong>€157m</strong></td>
<td><strong>32</strong></td>
<td><strong>15</strong></td>
<td><strong>€40m</strong></td>
<td><strong>17%</strong></td>
</tr>
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</table>
Encouraging deeper levels of collaboration for research groups

JPND Online Partnering Tool

Welcome to the JPND Partnering Tool | About the tool

Looking for partners for your project?
With the JPND partner finder, it is easy to register your research group's experience, and get an overview of other registered groups.

Register research group  |  Search for partners

Need more information about the tool?
For more information about how to use the tool, please view our Video Tutorials describing the different possibilities and features.

Cross-Disease Analysis of Pathways  |  Preventive Strategies

Have a proposal idea for a JPND call?
Registering a proposal idea for a JPND call is the first step towards drafting a proposal online using this tool. Once your idea is registered, you can choose to make it visible to all users to gain interest and feedback, or you can form private consortia around it, inviting selected partners to join, potentially leading to the drafting of a proposal.

To register a proposal idea, click on the relevant button below:

Browse research groups

<table>
<thead>
<tr>
<th>Group Name</th>
<th>Last updated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Molecular mechanisms underlying cerebellar ataxia</td>
<td>1/20/2014</td>
</tr>
<tr>
<td>Canine models of human neurodegenerative disorders @ University of Helsinki, Finland</td>
<td>1/20/2014</td>
</tr>
<tr>
<td>Electrophysiology and optogenetics in behaving mice</td>
<td>1/20/2014</td>
</tr>
</tbody>
</table>

Browse proposal ideas

<table>
<thead>
<tr>
<th>Proposal Title</th>
<th>Last updated</th>
</tr>
</thead>
<tbody>
<tr>
<td>Involvement of Impaired Lysosomal Flux in Neurodegenerative Diseases</td>
<td>1/1/2014</td>
</tr>
<tr>
<td>Embodied Movement Prevention for Parkinson Disease</td>
<td>1/1/2014</td>
</tr>
<tr>
<td>Boosting mitochondrial capacity in neurodegenerative diseases</td>
<td>1/1/2014</td>
</tr>
</tbody>
</table>
JPND Member Countries Plans

Have ND-related strategies

No plans to develop strategies

Oct 2009
JPND Member Countries

Have ND-related strategies

Promoting discussions

No plans to develop strategies

Feb 2014
Appropriate areas for alignment

- Linking, harmonizing and sharing information between (ND-directed) investments under national programmes
  - e.g. alignment of funding decisions in each country, on an annual basis

- Defining approaches that facilitate wider access to national technology platforms / infrastructures and promote the sharing of data and resources
  - e.g. biobanking, neuroimaging or informatics capabilities

- Identifying capacity-building approaches to facilitate better networking across and between disciplines and researchers
  - In particular for ND-relevant clinical, healthcare and social care sectors
ERA-level

- Establish a programme of co-investment with EC
- Work towards a sustained increase of investments from JPND partners
- Leverage the value of investments and resources at both national and EC level, to the benefit of Europe

**Examples:**
- Synergy between JPND actions and H2020 programme
- Linking national plans through actions engaging national infrastructures
- Development and long term sustainability of European cohorts
- Unlocking national capability on fellowship programs
Partnership with the EC

- First call of Horizon 2020 (Dec. 2013)
- ERA-NET cofund:
  - “Establishing synergies between the Joint Programming on Neurodegenerative Diseases Research and Horizon 2020”.
  - Proposal should:
    - coordinate national and regional programmes for research in the area of ND diseases research by implementing a transnational call with EU co-funding

- Potential call topics:
  - Identification of genetic, epigenetic and environmental risk + protective factors
  - Longitudinal cohorts in ND research
  - Advanced experimental models of ND

- Top up funding allocated = 10 M€ for JPCofuND
The summit on 11 December brings together G8 ministers and other delegates to discuss dementia.

- In response, the OECD is launching a project in 2014 for research on Alzheimer’s and dementia:
  - Aimed at strengthening international collaboration and promoting data sharing at the international level
  - JPND invited to join the project Advisory Group and Philippe Amouyel is member of the World Dementia Council
Partnership with non-European countries

- JPND Third Country Policy
  - Canada joined in June 2012

- Ongoing discussions with the USA
  - Presentation of JPND in Washington at the AAAC building with various federal institutions, scientists, non-profit organisations
  - Meeting being organised in the next few weeks between JPND members and US federal institutions and non-profit organisations

- Discussion initiated with the G8/7 countries

- May be Latin America and Caribbean?
Partnership with Latin America and Caribbean

Some areas of high added value are the following:

- Population with different genetic and environmental backgrounds would serve as models of healthy ageing and ND.
- The creation of a stroke bio bank in the EU-LAC region would have a special value for searching useful biochemical and genetic markers in stroke.
- The use of existing Information and Communications Technologies (ICTs) in order to improve the management of ND, mainly prevalent disorders such as stroke and dementias.
- Epidemiological Monitoring: prevalence and incidence of the ND in both region and evaluating public health prevention activities.
To move ND research up the EU agenda

Investing less than the USA

Low co-ordination / High fragmentation

From EU COM (2008) 468
Joining forces to fight neurodegenerative diseases

‘We hope that JPND will be a successful pilot for research into other challenges, as well as lead to a reduction in the burden of neurodegenerative diseases.’
Keep up to date

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

- Sign up to the JPND News Feeds

- Follow JPND Progress pages

- E-mail us: secretariat@jpnd.eu

- Follow us on Twitter: @JPNDEurope