

New Care and Prevention Models
3rd Global Dementia Legacy meeting



Joint Programming in Neurodegenerative Disease Research (JPND)

Coordinating approaches to research across Europe

Prof. Philippe Amouyel, MD, PhD JPND Chair Tokyo, November6th, 2014



JPND research

What is Joint Programming in Research?

Three pilars

- •A shared vision: 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





We cannot tackle neurodegenerative diseases by acting as single countries

JPND is the largest global ND research initiative led by countries, with 28 participating

EU member states

Associated countries

Third countries :

Increasing coordination of national research programmes to improve impact and effectiveness

Albania Austria Belgium Canada Croatia Czech Republic **Denmark Finland France** Germany Greece Hungary Ireland Israel Italy Luxembourg **Netherlands** Norway **Poland Portugal** Romania Slovakia Slovenia Spain **Sweden Turkey United Kingdom**



The JPND 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







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





Neurodegenerative Diseases?

•The neurodegenerative diseases that JPND focuses on are:

- Alzheimer's disease (AD) and other dementias
- Parkinson's disease (PD) and PD-related disorders
- Prion disease
- Motor neurone diseases (MND)
- Huntington's Disease (HD)
- Spinocerebellar ataxia (SCA)
- Spinal muscular atrophy (SMA)









Scientific

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

Medical

- > Early diagnosis
- Prevention
- Clinical trials

Social

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



Defragmentation

- what JPND is all about...









STRATEGIC RESEARCH AGENDA





JPND Research Strategy (SRA)

- Agreed by all JPND Member States + Assoc. 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



SRA Implementation (2012-2014)

Annual Calls for Proposals



| Year | Total fund available | Research Area | No. of Projects |
|-----------------|-------------------------|---|-----------------|
| 2011 (pilot) | €16M | Optimization of biomarkers + harmonization of their use | 4 |
| 2012 | €18M | Risk and Protective Factors | 5 |
| 2012 | €11M | Evaluation of Healthcare | 6 |
| 2013 | €12M | Cross-Disease Analysis | 10 |
| 2013 | €11M | Preventive Strategies | 5 |

Centres of Excellence in Neurodegeneration (CoEN)

| 2011 | €6M | Phase I: common resources and methodological approaches | 8 |
|---------|-----|---|---|
| 2012-13 | €8M | Phase II: "Pathfinder" projects | 5 |



Call statistics

| Year | Call area of interest | No. of proposals submitted | Budget requested (million €) | No. of proposals recommended for funding | No. of proposals supported | Budget supported (million €) | Success rate (%) |
|-------|-----------------------------|----------------------------|------------------------------------|--|----------------------------|------------------------------------|---------------------|
| 2011 | Harmonization of Biomarkers | 14 | €31 | 5 | 4 | €14 | 29% |
| 2012 | Risk and Protective Factors | 52 | €97 | 18 | 5 | €17 | 10% |
| 2012 | Healthcare Evaluation | 22 | €29 | 9 | 6 | €9 | 27% |
| 2013 | Cross-Disease Analysis | 90* | €112 | 23 | 10 | €12.5 | 11% |
| 2013 | Preventive Strategies | 35* | €36 | 5 | 5 | €7 | 14% |
| Total | | 213 | €157m | 60 | 30 | €59.5m | 18% |

^{*} pre-proposals

JPND-supported projects in Preventive Strategies



EURO-SCD:

Subjective cognitive decline in preclinical Alzheimer's Disease: European initiative on harmonization and on a lifestyle-based prevention strategy (Coordinator: Frank Jessen, Germany)

MIND-AD:

Multimodal preventive trials for Alzheimer's Disease: towards multinational strategies (Coordinator: Mia Kivipelto, Finland)

NEUROEXERCISE:

The effects of an extensive exercise program on the progression of mild cognitive impairment (MCI) (Coordinator: Stefan Schneider, Germany)

ONWebDUALS:

ONTology-based Web Database for Understanding Amyotrophic Lateral Sclerosis (Coordinator: Mamede de Carvalho, Portugal)

PreFrontAls:

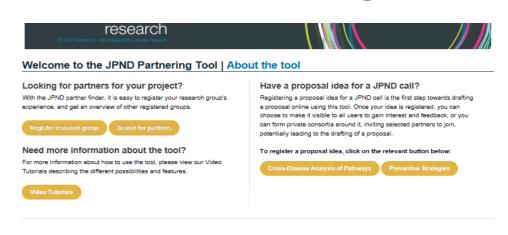
Searching for therapeutic interventions in frontotemporal dementia with C9ORF72 repeat expansions in the presymptomatic stage (Coordinator: John C van Swieten, The Netherlands)



Encouraging deeper levels of collaboration for research groups

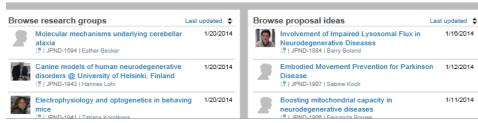


JPND Online Partnering Tool







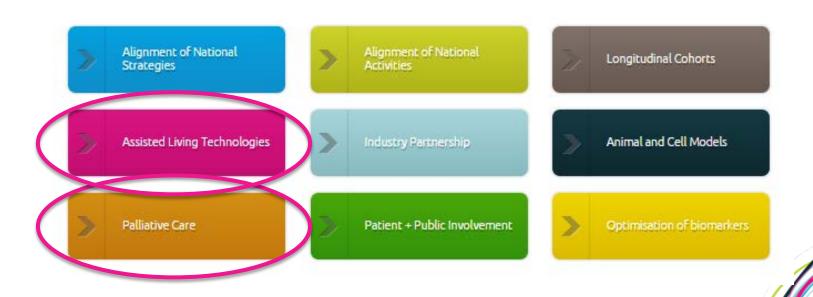






JPND Alignment Actions

JPND Action Groups for:





Action Group Recommendations





Assisted Living Technologies





Call 1: Chronic Conditions



Call 2: Social Interaction



Call 3: Self-Serve Society



Call 4: Mobility



Call 5: Home Care



Call 6: Occupation in Life



Innovation For Our Future



30 focused in dementia out of 150 AAL funded projects





- Distinct from cancer palliative care
- Advanced care planning
- Family involvement
- Cognition
- Difficult prognostication
- Important challenges:
 - how to shape palliative care through:
 - the stages of disease
 - the place of care
 - the key transitions more generally
 - optimizing care delivery through appropriate timing
 + integration of expertise
 - e.g. expertise in palliative, psychiatric, geriatric, dementia care, social and medical care



Participants at the JPND workshop, Amsterdam. June 25th. 2014







- Establish programme of co-investment to leverage the value of investments and resources at both national and EC level, to the benefit of Europe
- Synergy between JPND actions and H2020 programme
- First call of Horizon 2020 (Dec. 2013)
- ERA-NET cofund: Implementing a transnational call with EU co-funding
- Three Call Topics in preparation for the end 2014/beginning 2015:
- Identification of genetic, epigenetic and environmental risk + protective factors
- Longitudinal cohorts in ND research
- Advanced experimental models of ND





From G7 to JPND, a shared vision

| | G7 | JPND |
|--------------------------|-----|------|
| United Kingdom | YES | YES |
| France | YES | YES |
| Germany | YES | YES |
| Italy | YES | YES |
| Canada | YES | YES |
| United States of America | YES | - |
| Japan | YES | - |
| European Commission | YES | YES |





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