


Public and Patient Involvement in Neurodegenerative Disease Research (JPND)

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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)





We cannot tackle neurodegenerative diseases by acting as single countries

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

EU member states

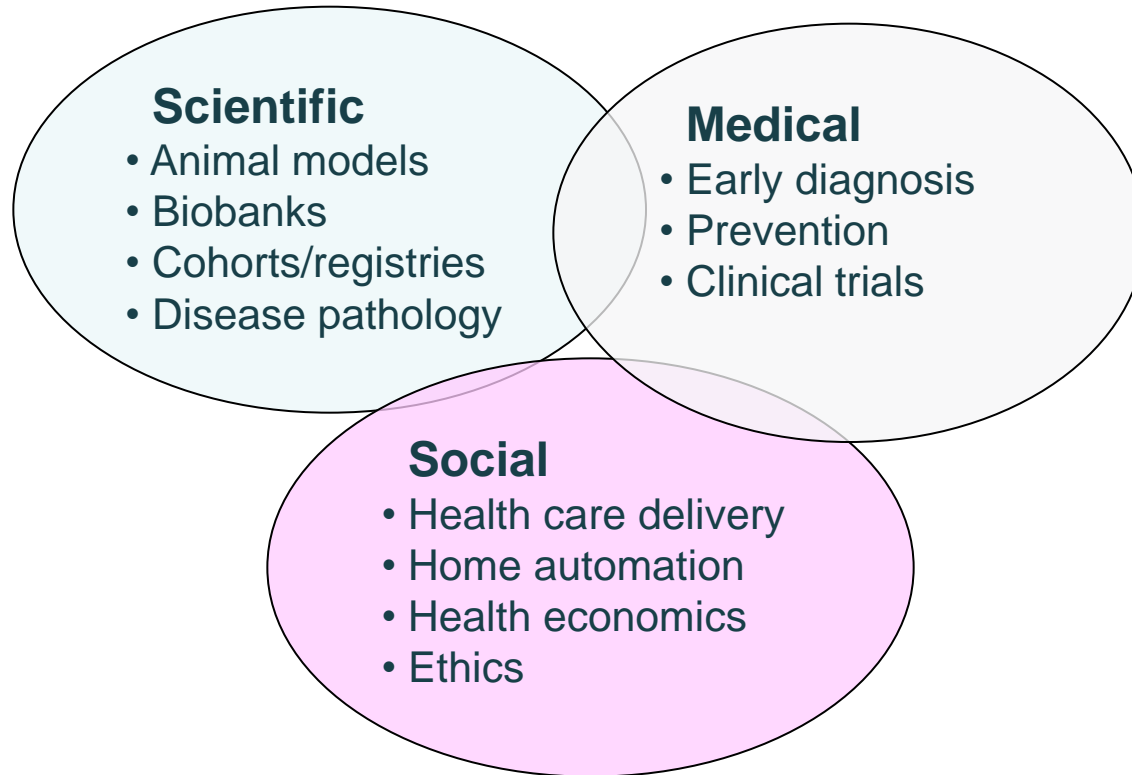
Associated countries

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
Switzerland
Turkey
United Kingdom

Scope of JPND



Why PPI in JPND?

Neurodegenerative Diseases

- have insidious onset
- inflict an enormous burden on patients, families, carers

Clear argument for active patient and public involvement in JPND research initiatives



Existing Guidelines + Good Practices

- **GUIDELINES**

- EPF Value+ (FP7)
- PatientPartner (FP7)
- EUPATI (IMI)
- Netherlands (ZonMw)
- INVOLVE (UK)



Value+

Promoting Patient Involvement in EU-Supported Health-Related Projects



Patient Partner



EUPATI

European Patients' Academy
on Therapeutic Innovation



Welcome to INVOLVE...

- **GOOD PRACTICES**

- Alzheimer Europe
- European Parkinson Disease Association (EPDA)
- **DeNDroN (UK)**

Framework for JPND PPI

- Differences in culture and tradition across JPND member countries must be considered.
- Cross cultural and social differences will have an impact on the way individuals with ND become visible and are accepted or stigmatized.



JPND : PPI in *Study Development*

- Surveys can help to identify common patient and carer priorities
- Advice from PPI can improve the relevance inclusion and exclusion criteria and appropriateness of a study protocol
- Patients and carers can assist with providing clarity to patient-facing information, ethical and informed consent issues, plans for dissemination and implementation of study outputs
- PPI can increase the feasibility and cost-effectiveness of studies, and their attractiveness to funders



JPND : PPI in *Study Delivery*

- Patients, carers can advise on reasonableness of recruitment strategies
 - e.g. how studies are explained to potential participants
- Good relationships with patient communities can help with publicity
- PPI can offer insights to help explain poor recruitment and retention rates
- Patients and carers can be part of study management and trial steering committees, and help with dissemination of results, implementation of study lessons



JPND:PPI Toolbox

- A. Guidance on finding lay members for panels
e.g. Trial Steering Committees
- B. Guidance on in-depth interview work with individuals/couples
- C. Guidance on running a research discussion group / focus group
- D. Using an ND patient/carer survey for PPI
- E. Working with Patient Representative Organisations



JPND: Implementation of PPI

- Should be part of JPND joint Calls
- Should be considered in other JPND Actions
- Should be presented to JPND Member
- Should be included in existing and upcoming National and Transnational Programs for ND



PPI : Think Global – Act Local

JPND–Europe +
Omeract-Global

Denmark

Norway

Netherlands

UK INVOLVE

PCORI -US



Learning from PCORI: Research informed by Patients

- *“We require that the proposals we fund include patients and other stakeholders in each step of the research process”*
 - *from proposal development to research design and dissemination of the study results*
- *Patients and other stakeholders also participate in the application review process*



Learning from PCORI: Planning the Study

Questions to be addressed by the researcher:

1. Identifying the topic, developing the research question?
 - *e.g. Epilepsy study: the patients and parents of patients with epilepsy pose the question: which anti-epileptic drugs best preserve sufficient cognition to go to work or school and function normally, while still preventing seizures adequately?*
2. How can you demonstrate this in your proposal?
 - *Interviewing patients with epilepsy*




PPI in Rheumatology A global Strategy

A powerful and important aspect of OMERACT is the integration of patients at each stage of the research process

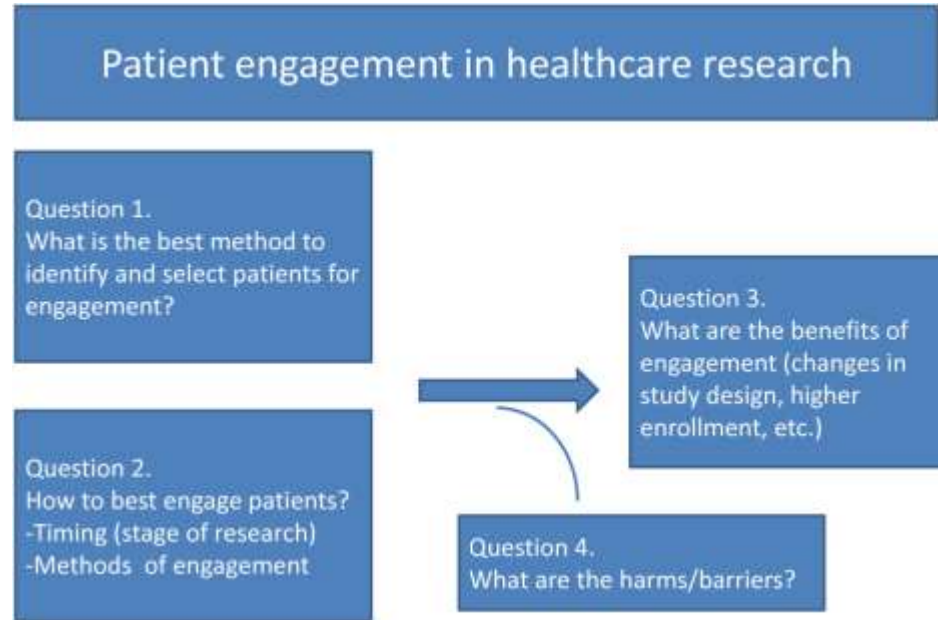


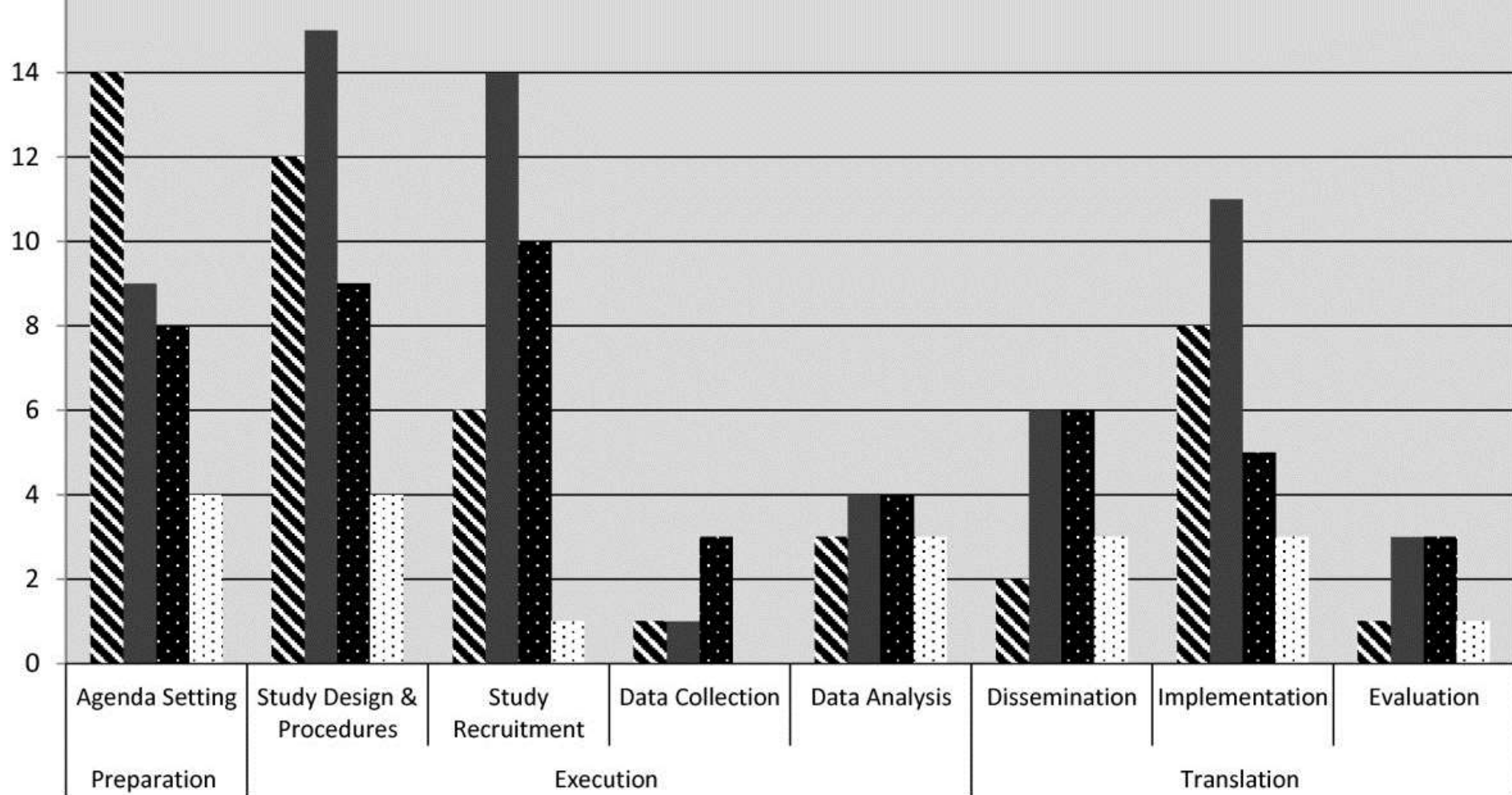
PPI in Research :Norway

- 2011 -the PPI concept introduced to representatives from *health care sector* and *research institutions*
 - 2012-2013 :Working groups by the two parts
 - 2014 : Recommendations presented and out for hearing
 - November 4th 2014: "From Words to Action"
 - Launch conference
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PPI Learning from Literature

*Patient
Engagement in
Research: A
Systematic
Review*
MH Murad et al
www.biomedcentral.com/1472-6963/14/89





PPI : Getting of the Ground

Key Stakeholders : Get together and agree on a common Strategy and Plan for Implementation

Research community : Identify Peers and good examples (they are around)

Develop Principles for Patients as Partners of Research. Alliance with charities



Major Challenges in PPI

“Involving patients actively in research represents a significant culture change and requires a number of barriers to be addressed including people’s attitudes and levels of awareness”

European Science Foundation, 2010

