Shared learning: How to apply PPI in multinational and multi-group research
Our next webinar

International PPI Network: Cochrane Learning Live webinar series

Thursday 9th November 2023, 14.00 UTC
The INCLUDE Ethnicity Framework, and other frameworks to improve trial diversity, & Pfizer’s commitment to achieve diversity in clinical trial
Shaun Treweek, Professor of Health Services Research, Health Services Research Unit, University of Aberdeen
Makeida Stubbs, Clinical Trial Diversity Lead for Internal Medicine, Anti-Infective, and Inflammation & Immunology, Pfizer

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Polls
Today’s presenters

Mogens Horder, Professor at the University of Southern Denmark

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Shared Learning:

PPI in multinational and multidisciplinary research groups

Mogens Hørder and Alexandra Rodrigues
University of Southern Denmark (SDU)

Cochrane PPI Webinar Series, 11th of October 2023
Summary of this webinar

1. What is JPND
2. PPI in JPND Calls
3. Challenges for PPI in JPND
4. The need for a PPI Network
5. Chatting with the audience
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1. What is JPND
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Joint programming is a *Member States-led* initiative born 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
Internationalisation: Europe and beyond

JPND is the largest global global research initiative aimed at tackling the challenge of ND led by EU countries, with 30 participating

- EU member states
- Associated countries
- Partner countries

Collaboration with USA NIH since 2018
Exploring potential for future collaboration with
- EU13 countries
- Brazil
- China
- India
- Japan
- Singapore
- South Korea
Scope of the JPND initiative

**ND diseases 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)

**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
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The process of PPI in JPND Calls

PPI is not an algorithm, it’s a learning process with and for people

PPI in JPND in 5 non-linear steps

1. 2015-Guidelines, first evaluation PPI in research proposals, PPI Advisory Board (Top-Down)

2. From 2018-PPI in the JPND Call texts
   • Systematic qualitative internal review
   • Qualitative Review of PPI (A, B, C)
   • Reporting from researchers
PPI in JPND Calls

PPI in JPND in 5 non-linear steps

3. The need of a PPI Network (Bottom-Up)
4. 2023- Ongoing development of an international PPI Network
5. Involvement of members of the PPI network in the external evaluation of proposals
6. Shared Learning of PPI in Research: between the PPI Network and JPND research community

PPI is a learning process. We learn by doing it.
1. What is JPND

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3. Challenges for PPI in JPND

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5. Chatting with the audience
“Consortia are expected to involve patients and carers where appropriate, at each stage of the research process.”

Too simplistic, tokenistic, lacking value/meaning

Moving from a "nice to have" to a meaningful "must have" element of good-quality research on neurodegenerative diseases.

Challenges for PPI in JPND funded research

- Disease heterogeneity (Ataxias vs Dementias)
- Diversity of research topics (from *in vitro* to HeSoCa)
- Multinational, multicultural and multidisciplinary research groups
- Wide variation in experiences with PPI among members of the research groups.
- Lacking feedback on PPI (implementation, challenges, impact…)
Abundance of guidelines on PPI for applicants

Topdown approach
Summary of this webinar

1. What is JPND
2. PPI in JPND Calls
3. Challenges for PPI in JPND
4. The need for sharing experiences with a PPI Network
5. Chatting with the audience
The need to learn what is the impact from PPI

Were all countries of the consortia represented in PPI? How were integrate PP from different countries, cultures and backgrounds? Did they learn from each other?

What was the final impact of PPI in the outcome of the research? And on patients and carers?

How did PPI partners communicate during and after the project is finished?

Did you share the outcomes with the PP in your PPI team?
The need to assess the impact of PPI
More reporting for researcher… No, please!

1-In which stages have patient and relatives been partners the project?

2-How have advices from patient and relative partners changed the research done?

3-How feedback given to the Patient Partners impacted their lives?

4-Please rate the impact of PPI from strong (5) to weak (1).

Researchers need support with PPI.
Need for a multinational, multicultural PPI NETWORK
Bottom up approach

- Based on lived experiences, rather than institutional representativeness.

- Participation of the growing global community of JPND stakeholders and not restricted to European members only.
Building a multinational and multicultural PPI NETWORK

- Citizens diagnosed with ND and their carers
- Representatives from ND Patients and/or Patients Organisations and/or Carers
- Researchers on ND and Social Sciences, Healthcare Professionals, Social Workers, etc.
Building a multinational and multicultural PPI NETWORK (2022-ongoing)

- Share their lived experiences with PPI

- a source of external experts for the review of PPI as part of JPND Calls and assessing the impact of PPI in JPND funded research

- Interact with JPND funded researchers to provide advice on PPI

- Provide patient insights on setting priorities on future research topics

- Identify new developments in PPI and ensure their continuous integration into the JPND Strategy
How will we know if PPI is having an impact?

If diverse PPI partners are sharing their learned experiences, gaining new insights and adapting practices—then it’s working!

Staley (2015), Research Involvement and Engagement, 1:6
PPI is a learning process.

We learn PPI by doing PPI:

• Topdown Approach: guidelines, publications
• Bottom Up approach: Multinational, multicultural PPI Network
• Transversally: Among PPI partners
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Q &A
Thank you

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