

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



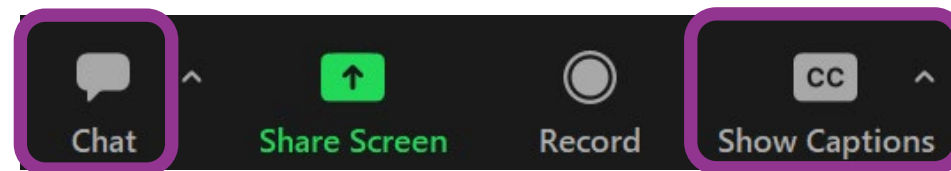
INTERNATIONAL PPI NETWORK WEBINAR PROGRAMME

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Zoom

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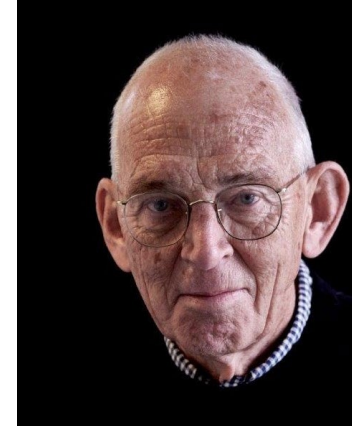


Polls



Today's presenters

Mogens Horder, Professor at the University of Southern Denmark



Alexandra Alves-Rodrigues Department of Public Health, University of Southern Denmark





JPND
research

EU Joint Programme – Neurodegenerative Disease Research

Shared Learning: PPI in multinational and multidisciplinary research groups

Mogens Hørdér 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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The Joint Programming Concept

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 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

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

Scope of the JPND initiative

Focus on Three Domains

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)

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

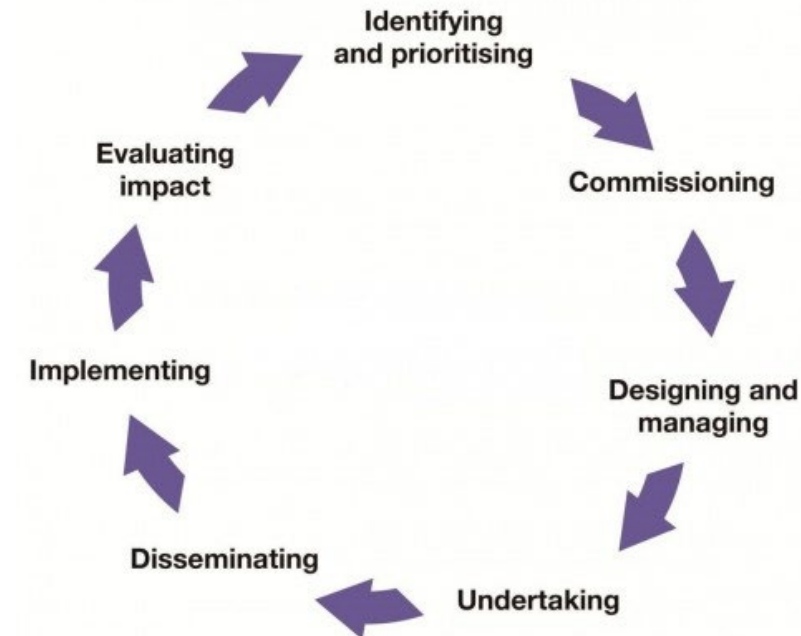
- Systematic qualitative internal review
- Qualitative Review of PPI (A, B, C)
- Reporting from researchers



PPI in JPND Calls

PPI in JPND in 5 non-linear steps

3. The need of 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.



JPND
research

EU Joint Programme – Neurodegenerative Disease Research

Alexandra Alves-Rodrigues

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Early PPI in call procedures

*“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



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PPI Instructions for full applications May 13 2015

For full applications only

Created with assistance from Arthritis Research UK

Research Involvement and Engagement

Home About Article Submission Guidelines

Methodology | Open Access | Published: 02 August 2017

GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research

S. Mariszewska, L. Brett, L. Simera, K. Seers, C. Mockford, S. Goodall, D. G. Altman, O. Mohr, S. Barber, S. Denegri, A. Fontaine, P. Littlejohns, C. Morin, B. Sulman, Y. Thomas & C. Tsaflis

Research Involvement and Engagement | Article number: 13 (2017) | Cite this article
158 Accesses | 158 Citations | 82 Altmetrics | Metrics

Abstract

Background

While the patient and public involvement (PPI) evidence base has expanded over the past decade, the quality of reporting within papers is often inconsistent, limiting our understanding of how it works, in what context, for whom, and why.

Objective

To develop international consensus on the key items to report to enhance the quality, transparency, and consistency of the PPI evidence base. To collaboratively involve patients as research partners at all stages in the development of GRIPP2.

Methods

The EQUATOR method for developing reporting guidelines was used. The original GRIPP (Guidance for Reporting Involvement of Patients and the Public) checklist was revised, based on updated systematic review evidence. A three round Delphi survey was used to develop consensus on items to be included in the guideline. A subsequent face-to-face meeting produced agreement on items not reaching consensus during the Delphi process.

Results

One hundred forty-three participants agreed to participate in round one, with an 86%

BMC Rheumatol. 2023; 7: 2. Published online 2023 Mar 9. doi: [10.1186/s41927-023-00327-w](https://doi.org/10.1186/s41927-023-00327-w)

PMCID: PMC9996937 | PMID: [36895053](https://pubmed.ncbi.nlm.nih.gov/36895053/)

Patient and public involvement in research: a review of practical resources for young investigators

[Ashokan Arumugam](#),^{1,2,3,4}

[Lawrence Rick Phillips](#),⁵ [Ann Moore](#),⁶

[Senthil D. Kumaran](#),⁷

[Kesava Kovanur Sampath](#),⁸ [Filippo Migliorini](#),⁹

[Nicola Maffulli](#),^{10,11,12}

[Bathri Narayanan Ranganadhababu](#),¹³

[Fatma Hegazy](#),^{1,2} and [Angie Botto-](#)

[van Bemden](#)^{14,15,16,17}

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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



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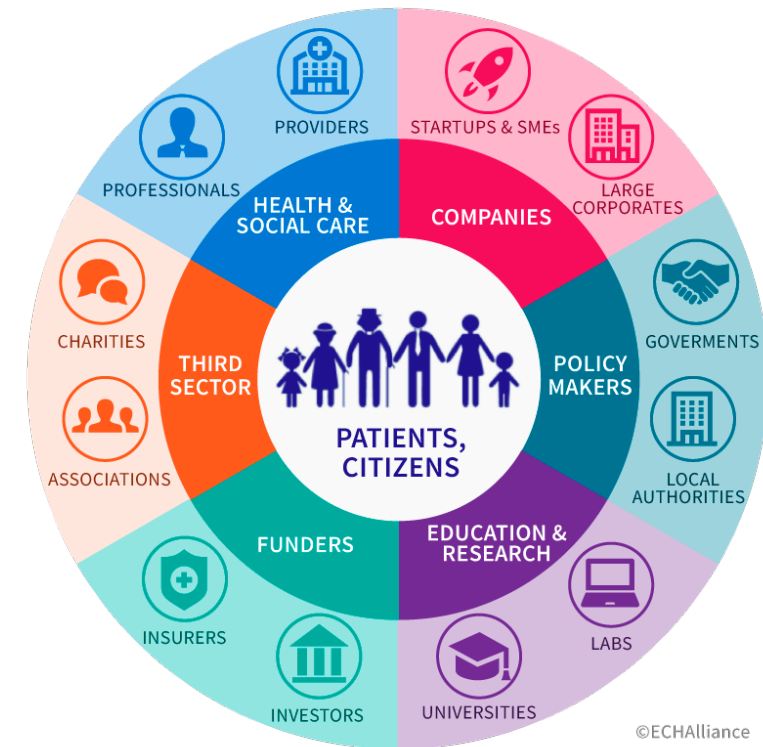
Bottom up approach

- Based on lived experiences, rather than institutional representativeness.
- Participation of the growing global community of JPND stakeholders and not restricted to European members only.



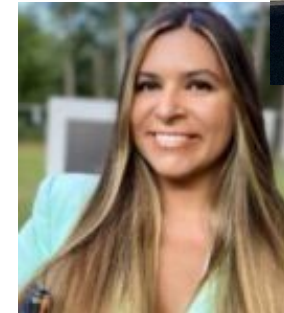
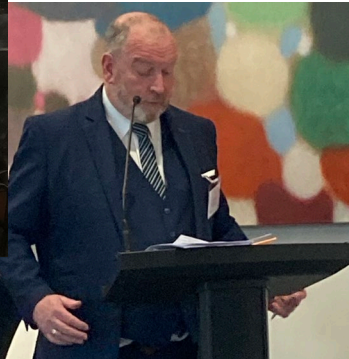
Building a multinational and multicultural PPI NETWORK

- 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.

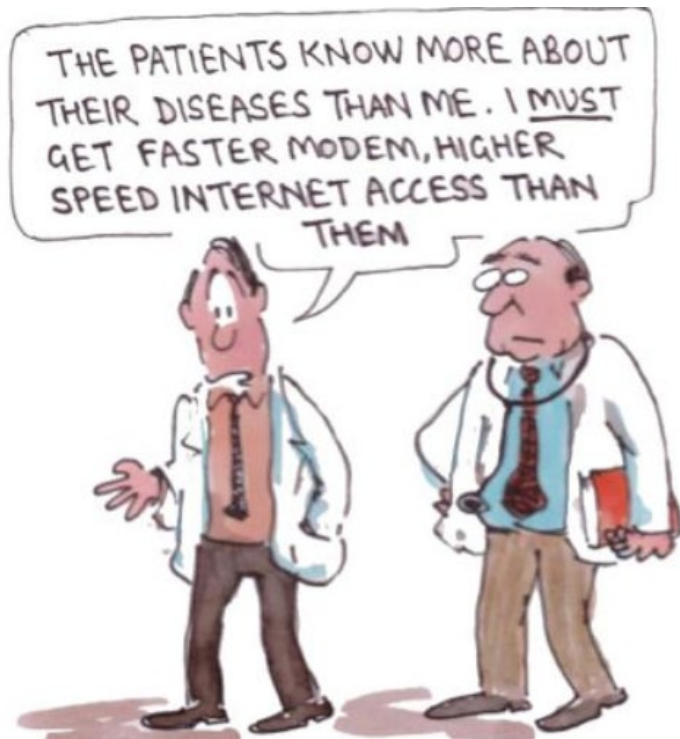


Building a multinational and multicultural PPI NETWORK (2022-ongoing)

- 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



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