JPND
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EU Joint Programme – Neurodegenerative Disease Research

WORKSHOP on

Patient and Public Involvement (PPI) in Neurodegenerative Disease Research

JPND Calls 2015-2019 and onwards

Mogens Hørder and Alexandra Rodrigues
Innovation Fund Denmark (IFD)

JPcofuND Symposium, November 27th and 28th,2019

2012 : Aim for PPI in JPND Calls

Develop and disseminate best practices in PPI to support implementation in ND research among JPND member countries and internationally

Develop and support the implementation of PPI in JPND-supported research, focusing on areas of research where PPI is seen as essential.

STEP 1:

JPND Guidelines on PPI for applicants

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Patient and Public Involvement in JPND Research

January 5
2015

A user-friendly guide for applicants to JPND Calls for proposals

Created in conjunction with DenDRoN, United Kingdom

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PPI Instructions for full applications

May 13
2015

For full applications only

Created with assistance from Arthritis Research UK

The first PPI assessment of a JPND Call 2015

The Topics of the 2015 JPND Transnational call

Longitudinal Cohort Approaches

Advanced Experimental Models

Risk and Protective Factors

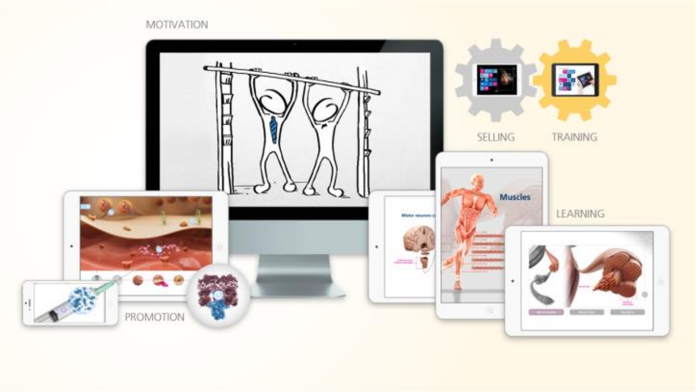
The plan for PPI was assessed by a separate panel of PPI Reviewers

2 reviewers for each application

- Reviewers from UK, NL, DK.
- Patients,carers and professionals

Challenges from Implementation of PPI

- Complexity of call Topics (Basic vs Care)
- Disease heterogeneity (Ataxia vs Dementia)
- Transnational Consortia apply for funding
- Wide variation in experiences with PPI



STEP 2

PPI in the Text of JPND 2018 & 2019 Call T

Consortia are expected to **make every effort to involve patients,relatives and carers where appropriate, at each stage of the research process including the preparation of the application**.

Please consult the ”JPND Guidelines for PPI ”

STEP 3 :
Systematic Review by the PPI secretariat

Qualitative rating on how PPI is applied in the application:

A. **The PPI approach is satisfactory.**

B. **Improvement of the PPI approach is recommended**

C. **The PPI approach is absent.**

STEP 3
Systematic Review of PPI (2018 & 2019 Calls)

A. Are there plans to involve patients/carers in the planning and conduct of the research project?	PPI has contributed to the preparation of the application (Y/N) PPI is planned for the Conduct (Y/N)
B. If YES , in which steps of the research process are patients/carers planned to be involved:	PPI indicators: •**Project design**: •Development of study tools: •Recruitment: •Data collection: •Analysis of data: •**Writing and dissemination:** •Implementation: .

STEP 3
Ratings of PPI in applications 2018 &19

PPI Ratings of 18 applications (2018)

A Rating :14 (Satisfactory)
B Rating : 3 (Improvement recommended)
C Rating : 1 (Absent)

PPI Ratings of 37 Applications (2019)

A Rating : 18 (Satisfactory)
B Rating : 19 (Improvement recommended)
C Rating : 0 (Absent)

STEP 4

A) Follow up on the implementation of PPI (Year 1 and 4)

In which stages of the research has PPI been applied ?

Has the consortium implemented PPI as described in the final, full application ?

If not -which changes have been made ?

STEP 4
B) Organisation of PPI (Follow up Year 1 and 4)

Has the consortium established an organization for PPI : Yes or No

If Yes-How is PPI organized and coordinated among the individual projects /nations/ WPs?

From where and how are the patients, relatives and citizens recruited as partners for PPI ?

Has the consortium recruited Patient partners from all participating nations , from a few or only from one country

STEP 4
C) Impact of PPI (Follow up Year 4)

In which stages of the projects have patient and relatives been partners in the planning and conduct of the project ?

Describe if and how advice from patient and relative partners has changed the research

Describe if and how a feedback been given to the Patient Partners on the impact of their advice

Please rate the impact of PPI from strong(5) to weak (1) and Describe the Impact according to table 2 of GRIPP 2 (ref)

STEP 5
Shared Learning of PPI: a JPND Research Culture

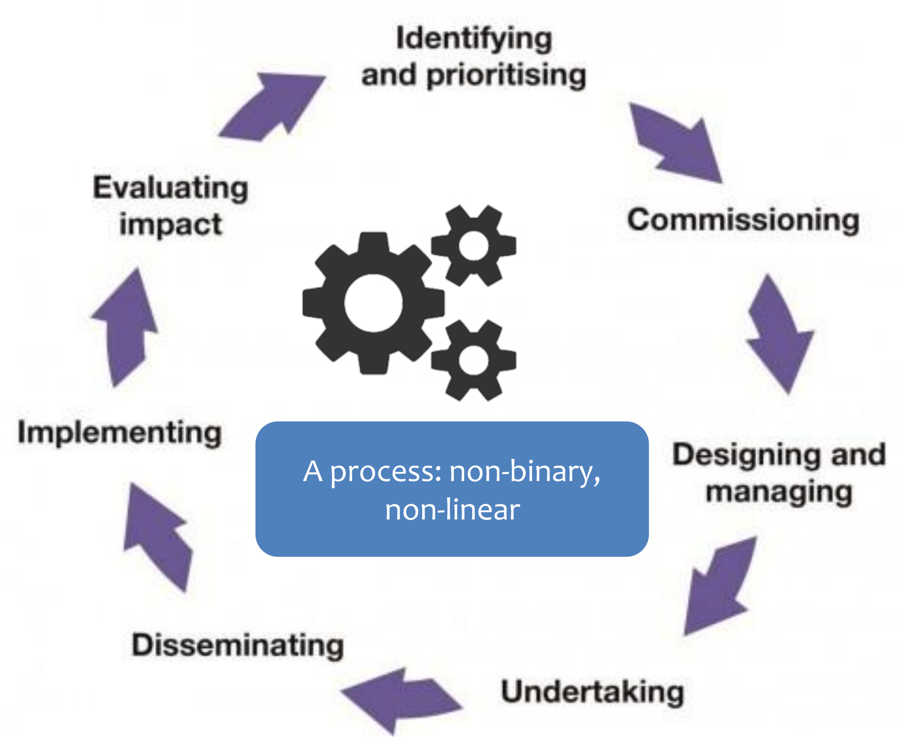
Establish a JPND Knowledge base on PPI:

Reports from Year 1 and Year 4 follow up of PPI of JPND projects are made available for sharing among researchers

Establish Webinars on PPI for based on the JPND Knowledge base on PPI

Participants: Researchers and their Patient research partners in year 1 of the project
Hosting the webinars are Year 4 -6 researchers and their patient partners

PPI is a learning process.



Identifying and prioritising

Commissioning

Designing and managing

Undertaking

Disseminating

Implementing

Evaluating impact

A process: non-binary, non-linear

We learn while doing it.

Reflections on JPND PPI and experiences with PPI
Patient and Carer Perspectives

Martin Rossor University College London, UK. Member of JPND SAB

Saskia Danen Nurse, Members of ZonMw committee national programme ‘Memorabel’ on dementia Alzheimer Netherlands / caretaker and

Ben Hoetjes, political scientist and caretaker.
Members of ZonMw committee national programme ‘Memorabel’ on dementia

Marco Blom Alzheimer Netherlands, JPND Stakeholder Advisory Board

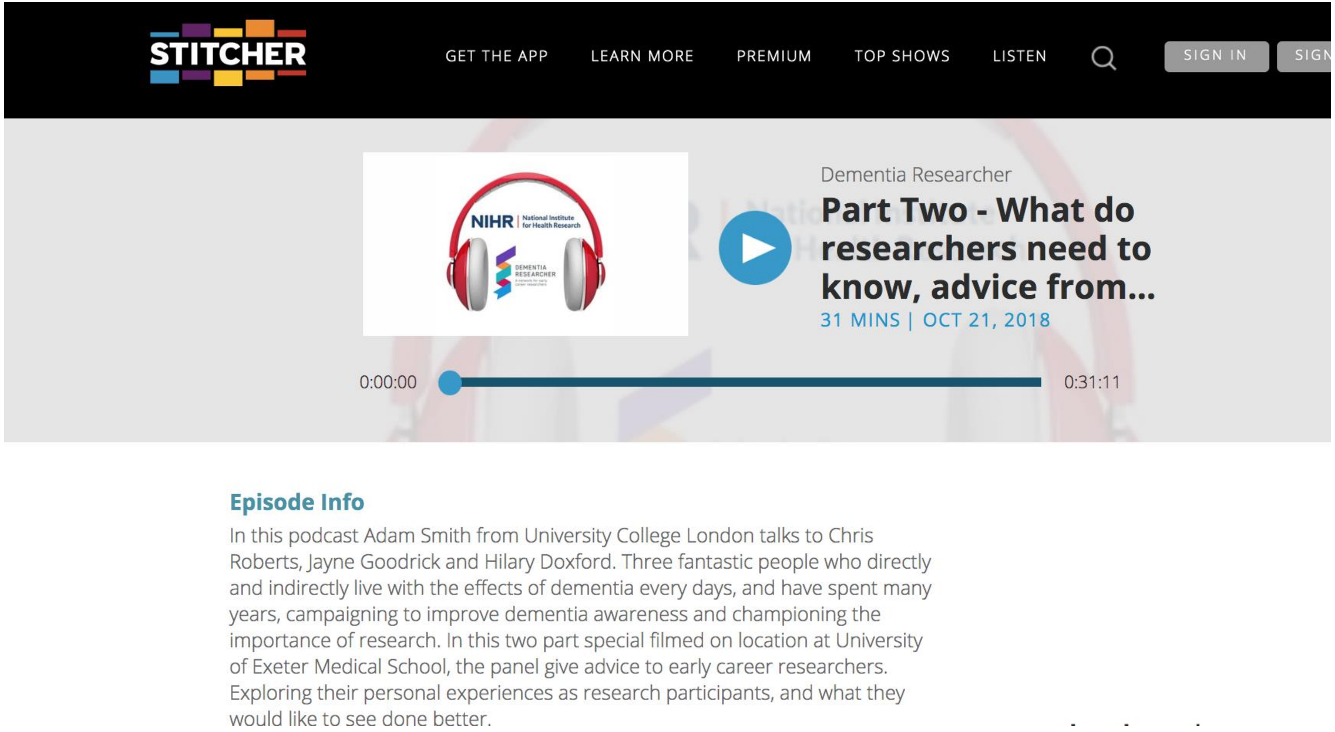
Patients and Carer Perspectives:

Chris Roberts and Jayne Goodrick

European Working Group of People with Dementia - EWGPWD

Dementia Researcher Podcast

21Oct2018



Dementia Researcher

Part Two - What do researchers need to know, advice from...

31 MINS | OCT 21, 2018

Episode Info

In this podcast Adam Smith from University College London talks to Chris Roberts, Jayne Goodrick and Hilary Doxford. Three fantastic people who directly and indirectly live with the effects of dementia every days, and have spent many years, campaigning to improve dementia awareness and championing the importance of research. In this two part special filmed on location at University of Exeter Medical School, the panel give advice to early career researchers. Exploring their personal experiences as research participants, and what they would like to see done better.

https://www.stitcher.com/podcast/managing-a-clinical-and-research-career/e/56829394?autoplay=true

From policy to learning
PPI in 5 steps

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1 The JPND policy on PPI:

The JPND 2015 and Alzheimer Europe 2017 Guidelines

2 PPI in JPND calls

Describe plans for PPI in the applications

3 Review of PPI in the application

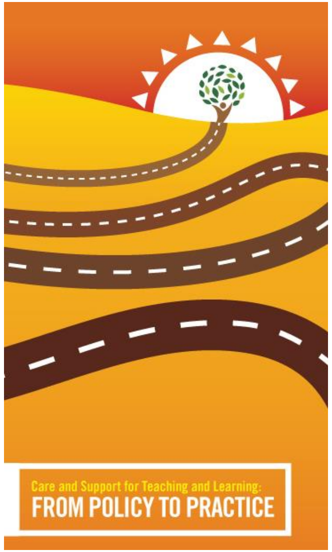
Systematic review for PPI of developments and conducts

4 Follow up on PPI

Year 1 and 4 reports on PPI from the funded projects

5 Shared learning of PPI

Open database of Year 1 and 4 PPI reports – and PPI webinars


Care and Support for Teaching and Learning:
FROM POLICY TO PRACTICE

How will I know if PPI is having an impact?

If you are learning, gaining new insights, changing your ideas and plans – then it’s working.

Staley (2015), Research Involvement and Engagement,1:6

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