



# JPND

## research

EU Joint Programme – Neurodegenerative Disease Research

# Patient and Public Involvement in JPND Research

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

Created in  
conjunction  
with DenDRoN,  
United  
Kingdom

## Purpose

The purpose of this guide is to provide clear, practical advice on how to involve patients with lived experience of neurodegenerative diseases (ND), their family members and caregivers, and the organizations that represent them, in research studies supported by JPND.

Specifically, this is a guide for applicants, reviewers, and successful awardees within JPND calls for proposals regarding patient and public involvement (PPI) in the conduct of JPND-supported research.

This guide is not intended to be comprehensive or prescriptive, but provides options to incorporate PPI, where relevant, into the research process. Applicants to JPND Calls may choose to include some activities listed here, and may include additional innovative approaches not listed.

## PPI Actions

In general, PPI actions under JPND-supported projects and initiatives should focus on three areas

- A. Research planning
- B. Research delivery
- C. Research dissemination

These areas provide the greatest scope for identifying patient and public participants for involvement, and for developing processes and methods for PPI.

Examples of PPI actions and how to demonstrate them in research proposals are contained in the tables below:

### A. Research Planning

Examples of PPI Actions	How to demonstrate in a proposal
<ul style="list-style-type: none"><li>Organise face-to-face discussions groups with ND patients and carers as efficient means to capture lay perspectives on the relevance of your research methods and outcome measures.</li><li>Organise one-to-one interviews for resource-effective, detailed consideration of the prospects of the research attracting funding. Other methods, such as surveys and email, are appropriate for patients or carers who cannot physically travel to meetings, or have speech or cognition problems.</li><li>Provide opportunities for patients and carers to assist with providing clarity to ethical and informed consent issues, plans for dissemination and implementation of study outputs. This input can increase the feasibility and cost-effectiveness of studies, and their attractiveness to funders.</li><li>For clinical studies, advice from PPI can improve the relevance inclusion and exclusion criteria and appropriateness of a study protocol.</li></ul>	<ul style="list-style-type: none"><li>Demonstrate how you are publicising opportunities for PPI in the development of your research proposal (e.g. distribution of flyers at clinical/research sites, or via patient-representative organisations at local/national level).</li><li>Provide letters of support from patients and carers that describe the origin of the proposal, the role of the patients in defining the question, outcomes, comparators, and goals/outcomes, etc.</li><li>Alongside relationships with lay individuals, describe how you plan to establish ongoing working agreements around PPI with ND-relevant patient organisations such as medical charities.</li><li>Detail how you will link your PPI planning to your organisation's "communications" or "outreach" activities.</li></ul>

## B. Research Delivery

Examples of PPI Actions	How to demonstrate in a proposal
<ul style="list-style-type: none"> <li>Once an ND-related clinical, social or health service study is recruiting, lay people can still contribute creatively on the reasonableness of recruitment strategies, such as the planned approach to how studies are to be explained to potential participants.</li> <li>Where studies are failing to recruit sufficient patients, provide opportunities for individuals and organisations to offer insights to help explain poor recruitment and retention rates.</li> <li>Provide support mechanisms such as mentoring and training of individuals to go out into the community (e.g. through their own patient networks) to recruit study participants and to conduct interviews.</li> <li>Investigate whether your research-performing organisation could allocate a specific involvement liaison role within the organisation to coordinate PPI links.</li> </ul>	<ul style="list-style-type: none"> <li>Clearly articulate the roles of PPI individuals and organisations in each component of the study, (e.g., helping to draft survey tools and focus group questions, reviewing participant materials for readability, interacting with study participants (e.g., recruiting participants, conducting interviews, leading focus groups, etc.).</li> <li>Consider the appointment of suitable ND lay representatives to steering committees, or management groups in your proposal.</li> <li>Describe how you may discuss with lay people to creatively problem-solve for particular ND studies where recruitment/retention may be a problem.</li> </ul>

## C. Research Dissemination

Examples of PPI Actions	How to demonstrate in a proposal
<ul style="list-style-type: none"> <li>Include patients and carers as part of study management and steering committees, to help with dissemination of results, implementation of study lessons.</li> <li>Targeted PPI initiatives can help to extend the scope for ND research into new community environments, such as promoting ND research in care home settings, or addressing informed consent challenges.</li> <li>Good relationships with patient communities can help with publicity for research projects/initiatives.</li> <li>Input from PPI individuals and organisations can help design public-facing information.</li> <li>Within the range of lay people identified, some may have communications skills and media relations. Roles can be developed for them around becoming your ND research 'ambassadors'.</li> <li>If patients with an ND perspective, and carers, already have representative roles in a health and social care context, their capacity to become a valuable link for researchers should be encouraged.</li> </ul>	<ul style="list-style-type: none"> <li>Alongside relationships with lay individuals, describe how you plan to establish ongoing working agreements around PPI with ND-relevant patient organisations such as medical charities.</li> <li>Clearly articulate the roles of PPI individuals and organisations in each component of study dissemination, (e.g., helping to draft survey tools and focus group questions, reviewing participant materials for readability, designing public-facing information)</li> </ul>

## Important Notes:

- It is recommended that PPI actions be applied where the project consortium considers it will have greatest impact on the project outcomes, and also where it is economically and practically feasible.
- The JPND stakeholder advisory board on PPI is available to provide consultation and advice on PPI actions chosen by the project. Mogens Hørder, Chair of the PPI Advisory Board and Derick Mitchell, Senior JPND Communications Manager, are available as contact points in this regard. (Email: [mhorder@health.sdu.dk](mailto:mhorder@health.sdu.dk) and [dmitchell@jpnd.eu](mailto:dmitchell@jpnd.eu)).

## Toolbox for PPI in JPND-supported projects

The following methods and tools for PPI may act as a “toolbox” for JPND-supported projects and may also be used generically to facilitate lay involvement in research.

### A. *Guidance on finding lay members for panels, such as Clinical Trial Steering Committees*

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**A lay representative is an individual patient/carer who can provide patient/carer input as a member of a research development/delivery team, or is available for informal advice. An important criterion for lay representatives will be their lived experience and personal association with neurodegenerative diseases rather than their level of knowledge of research. A commitment from researchers to support and mentor lay representatives can overcome knowledge gaps. Carers and former carers are often well-placed to be representatives.**

Key considerations:

- The style and degree of formality of selection processes for individuals depends on the specific role. The core role of a patient/public member of a research operational team could be described as “to contribute to the work from the point of view of someone with direct or indirect experience of a neurodegenerative disease. The most important personal skill for the role is a willingness to bring to our planned research a balanced understanding of the wide range of different perspectives which ND patients, carers and the wider public will have”.
- For many researchers, the simplest route to finding people may be via distribution of flyers at existing clinical/research sites, or more widespread distribution via patient-representative organisations at local or national level.
- It may be that a face-to-face or telephone interview will allow assessment of an individual’s abilities, interests and relevant lived experience. Minimum criteria for IT skills and educational qualifications can be indicated, also in addition to any necessary confidentiality agreements.
- It is often appropriate to regard patient/public members as representing their individual viewpoints, even if they are identified via a representative organization.

### B. *Guidance on in-depth interview work with individuals/couples*

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**This personalised method is particularly appropriate for people with ND who are experiencing communication or cognitive problems. In-depth interviews are undertaken with one, two or three people for ‘reality-testing’ of aspects of your research proposal development. Unlike larger discussion focus groups, in-depth interviews allow detailed consideration by patients**

**and/or carers in order to relate the proposed research directly to their personal knowledge and experience of an illness or condition.**

Key considerations:

- Keep questions to a minimum but do use open questions to encourage the patient/carer to expand their story when appropriate.
- Broadly speaking, the interviewee(s) will do the bulk of the talking, and the success of such an interview is influenced by the sensitive use of the 'agenda' and demonstration of active listening skills by the interviewer.
- Prompt cards for the interview 'agenda' can be very helpful.
- The duration and timing should be kept relevant to the patient/carer's needs.
- An invitation letter could be distributed in specific clinics, or via patient-representative groups, to invite people to consider taking part in such in-depth interviews. A phrase such as *"Whether you decide to take part or not will not affect your individual treatment or care now or in the future"* should be considered as part of any invitation letter.
- An 'agenda' for discussing an ND research proposal, could ask the interviewee(s) to envisage the various stages of the experience of participation in such a study from a patient's perspective: For example; *"imagine being sent to a memory clinic with a provisional diagnosis, hearing of this research study at the clinic, what are your initial thoughts on the research, considering the pros and cons, imagine the process of deciding whether to participate in the research"*.

#### **C. *Guidance on running a research discussion group / focus group***

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**An interactive group of patients, carers, members of a research team, all exploring a specific research topic or range of issues, concerning a particular study or a large programme of research.**

Key considerations:

- A loose agenda allows a moderator to structure the discussion productively around key questions without unnecessary restriction.
- The agenda could, for example, look at study design dilemmas, potential recruitment problems, or examining relevance to patient benefit. Concerns around carer issues and confidentiality can often arise in ND research discussions, as well as the appropriate application of inclusion/exclusion criteria for those ND illnesses which progress rapidly.
- Plan appropriate venues and other arrangements specific for people with ND conditions. Participants may need prior briefing about the research under discussion.
- Encourage everyone to actively participate. Prompt cards are particularly useful to assist people with cognitive impairment to follow the flow of conversation.

#### **D. *Using an ND patient/carer survey***

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**For ND research proposals, ascertaining a range of lay opinions and ideas about research development or delivery can be very useful. Surveys and email consultation exercises are particularly valuable for involving patients and carers who physically cannot travel to meetings, or who have speech or cognition impairment problems.**

The aim of this type of involvement is to learn from opinions drawn from lay experience, to strengthen the relevance of the research activity. Deciding on which questions to include will depend on where researchers are most likely to benefit from lay opinions and ideas, and the appropriateness of the content for people living with ND conditions.

Short succinct surveys generally have better response rates. The survey covering explanation should include:

1. A summary of survey aims, time-lines for responses, any confidentiality issues.
2. A mixture of 'closed' response choices and 'open' free text questions often works well. Questions should aim to elicit opinions around, for example:
  - the rationale for the research, the overall design
  - explicit uncertainties or problems with aspects of the research proposal, where 'external' lay input might help to resolve
  - content of patient information sheets
  - whether the research methodology makes sense to lay people
  - whether a study seems likely to recruit sufficiently quicker/slower in real-life clinical settings
  - potential benefit for patients and carers, researchers, and Member State health and social care systems

#### **E. *Working with Patient Representative Organisations***

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**Each JPND member country has a wide range of directly-relevant charities, disease-specific groups and other stakeholder organisations which can offer valuable avenues for collaboration around PPI in research.**

Key considerations:

- Develop national-level working agreements with representative organisations/charities within JPND Member Countries. This can provide a sound basis for facilitating subsequent local-level working collaborations.
- Patient representative organisations may be happy to link with researchers around identifying individuals and groups for PPI activities. Within a charity, there may be a smaller sub-group organized specifically around research activities.
- As well as directly relevant medical charities, and disease-specific representative groups, there are other organisations which can contribute to advising and commenting on the design and delivery of ND research. e.g. organisations which work generically with carers or involving older people.
- It is generally helpful to view all patient/public members as representing their individual viewpoints. Patient/public members are usually chosen because of their individual experience. However, in practice, patient/public members may have been recommended by a specific medical charity, and naturally they will often aim to reflect that organisation's views. Patient/public members should be there to provide their individual views only, unless specified otherwise.

## JPND Goals and Objectives for PPI

JPND Management Board members have determined that PPI should be an integrated part of JPND activities and initiatives as part of the implementation of its Strategic Research Agenda.

A JPND Action Group has been established with the remit to “*promote Public Involvement in Research in order to improve the way that neurodegenerative disease research is Prioritized, Commissioned, Undertaken, Communicated and Used*”.

The Action Group was expanded in 2014 to form a **JPND PPI Stakeholder Advisory Board**, with the addition of senior leaders of relevant parts of the international scientific, clinical, healthcare and social care systems. The primary aim of the Board will be to provide rapid and frank feedback and early advice from the broad PPI stakeholder community to JPND in relation to implementation of PPI in ND research.

### Overall JPND Goals for PPI

*Goal 1: to integrate PPI in an appropriate manner in initiatives supported by JPND*

*Goal 2: to enable the implementation of PPI in national strategies and plans for ND research*

### Specific JPND PPI Objectives

- *to support the development of fundable, deliverable research*
- *to support the recruitment of patients and public to research studies*
- *to strengthen the ND research culture*

### JPND PPI Actions

In general, PPI actions for proposals submitted to JPND can be divided into two categories:

- *Identifying and maintaining meaningful relationships with patients and the public*
- *Developing processes and methods for PPI*

**More information on JPND PPI activities and strategies can be found on the JPND website:**

<http://www.neurodegenerationresearch.eu/initiatives/jpnd-alignment-actions/patient-public-involvement>

## Further sources of guidance for applicants

- [INVOLVE \(UK\) resource for researchers](#) (click to link to INVOLVE Website)  
*An online resource of briefing notes for researchers on how to involve members of the public in research. It includes:*
  - *supplements with detailed information on public involvement in specific types of research and on specific involvement activities*
  - *case studies showing how members of the public have been involved in research projects*
  - *templates of useful documents such as job descriptions and terms of reference for committees and steering groups*
- [PCORI Rubric for Patient and Family Engagement](#) (click to download a PDF copy)  
*A similar guide produced by the PCORI Initiative (USA)*