



JPND

research

EU Joint Programme – Neurodegenerative Disease Research

PPI Instructions for full applications

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For full applications only

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Purpose

The purpose of these instructions is to provide clear information on JPND expectations for the PPI section of full proposals submitted under certain topics as part of JPND calls for proposals.

Background

- For some JPND call topics, applicants are required to provide a section on appropriate Patient and Public involvement (PPI) within their application. The purpose of the PPI section is to allow assessment of the application by the JPND PPI review team. The section may also serve as the 'lay project description' for those patients, relatives and carers that are to be involved in the planning and delivery of the project.
- The PPI section will be reviewed by JPND-appointed PPI reviewers, comprising informed lay representatives and professionals with particular experience in judging PPI. These reviewers' remit is to consider the potential scientific, clinical and/or healthcare benefit of including advice from patients or relatives and carers in the planning and delivery of the project. The PPI assessment is considered formally by the Call Steering Committee.
- The PPI section should be written at the level of a science feature in a broadsheet newspaper. Minimal use of jargon or acronyms is important; where this is unavoidable, please provide explanations. Terms such as 'pathway', 'expression', and 'signalling' should be avoided or fully explained. There is no need to explain at length the generic importance or impact of the disease area you plan to investigate. The use of non-scientific analogies to explain complex ideas is encouraged. Images and diagrams are also acceptable as an aid, not an alternative, to narrative explanation.
- It is crucial that your PPI section conveys relevant information in a form comprehensible to a lay readership. We strongly advise that you "test" your PPI section with an informed lay reader before submission.

Your PPI section must specifically answer the questions set out below:

- (a) Provide a 'Lay Summary' of potential Clinical or Healthcare benefits (50-100 words)**
Provide a short explanation of how achieving your research objectives will benefit patients, either as a direct result of your findings, or to inform future research that may result in clinical or healthcare/social benefits.
- (b) What are the specific aims of the patient/public involvement (40 – 70 words)**
Briefly state the anticipated impact of the patient/public involvement in your project (i.e. what role will it play - for example, making the project aims more relevant; improving the project efficiency etc.).
- (c) How will you perform the PPI – (i.e. what approach to PPI will be used)? (40 – 70 words)**
JPND recommends that you consult the user-friendly JPND guide on how to involve patients, their family members and caregivers, and the organizations that represent them, in research studies. This guide is available for download from the JPND website at the link below.
- (d) How will the consortium evaluate it? (40 – 70 words)**
Explain how the consortium will monitor PPI during the project and evaluate the outcome and impact at the end.

You can download all JPND PPI Guidelines by clicking on the link below:

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