

## MANDATE, OBJECTIVES AND RULES OF PROCEDURE



### JPND PPI ADVISORY BOARD

#### I. GENERAL CONSIDERATIONS

A dedicated PPI Advisory Board is to be established, building on the work already undertaken by the JPND Action Group on PPI, to adequately implement PPI actions and activities in neurodegenerative disease (ND) research, to develop the necessary relationships and ensure continued dialogue between opinion leaders in the PPI field.

From a general viewpoint, the JPND PPI Advisory Board is a long-term JPND initiative, established to provide recommendations to the JPND Management Board (MB) on all matters of direct or indirect interest to patient/public stakeholders in relation to PPI in ND research and to perform the tasks described under section II.

In particular, the Board will look to make recommendations on how best to improve and implement the draft JPND PPI plan in the following areas:

- Patient and public involvement in JPND-supported research
- Patient and public involvement in national plans and initiatives relevant to ND
- Public communication and dissemination of ND research results
- Transparency for the life cycles of different ND research areas
- Relationship building and influencing of key opinion leaders within charities and patient organizations
- Raising public awareness of JPND

The recommendations will be achieved in a step-wise fashion through dialogue, counselling, consensus-building, networking and influencing.

#### II. MANDATE AND OBJECTIVES

The JPND PPI Advisory Board is established to provide advice and recommendations to the MB of JPND on request, on all matters of direct or indirect interest to patient and public stakeholders in relation to PPI in ND research including, but not limited to the tasks defined below:

**In a step-wise fashion, the PPI Advisory Board will:**

- Develop and support the implementation of PPI in JPND-supported research, focusing on areas of research where PPI is seen as essential.
- Develop and disseminate 'best PPI practices' to support implementation in ND research among JPND member countries and internationally
- Define performance indicators for monitoring and evaluation of the implementation of PPI actions

- Liaise with other relevant JPND Action Groups, coordinators of JPND-supported research projects and external groups where necessary, in relation to PPI
- Contribute to the development of appropriate communication tools
- Contribute to the provision of information adapted to patient, carer and public needs
- Contribute to the recruitment of participants to ND research activities (e.g. clinical trials)
- Identify new developments in PPI and ensure their continuous integration into the JPND plan for PPI
- Nominate experts, when necessary (see Rules of Procedure)

### III. COMPOSITION

The composition of the Board will be based on professional experience, rather than institutional representativeness. Composition should predominantly reflect European considerations, but should consider the participation of the global community of JPND stakeholders and not be restricted to European members only.

The Board will consist of appointed individuals who have been either nominated by MB members, or have been identified by the current PPI Action Group as key opinion leaders in this field. The Board should consist of a maximum of 10 to 12 key leaders – to be selected based on professional experience, from any of the following stakeholder groups, making efforts to ensure no country or stakeholder group is over-represented:

- Representatives from ND Patients and/or Patients’ Organisations and/or Carers
- Representatives from Publicly-funded Researchers (Clinicians, Healthcare Profs., Social Researchers)
- Representatives from Research-funding Organisations (may not necessarily be MB members)
- Representatives from organisations involved in generic PPI
- Representatives from National Plans and strategies related to neurodegenerative diseases

The current Action Group chair will act as chairperson to the board, and activities will be managed through a small secretariat, led by the Chairperson, JPND Senior Communications Manager, with (minimal) support from the JPND Secretariat.

The selection of appropriate candidates for the Board must ensure that experience on the international level is paramount. The current PPI Action Group will consult with JPND Steering Committee (SC) members on a shortlist of individuals prior to inviting members onto the Board on the basis of their appropriateness to the subjects covered within the scope of the Board’s mandate.

The final composition of the Board will be of a maximum of 12 representatives. Membership will be maintained at a limited number to ensure optimal efficiency. As members will not be representing their organisation, it is not their responsibility to provide the position of the organisation on the topics to be addressed. However, it is their responsibility to inform their respective organisation about the activities of the Board.

Membership of the Board implies a commitment to participate actively in the work involved and to attend the meetings of the Board regularly. After a member has presented their apologies three consecutive times, the membership will be revoked, and the Chairperson would consider participation of another individual.

Observers (e.g. JPND EB members) may participate with the agreement of the Chairperson. Meeting documentation will be distributed to the participants by the JPND Secretariat.

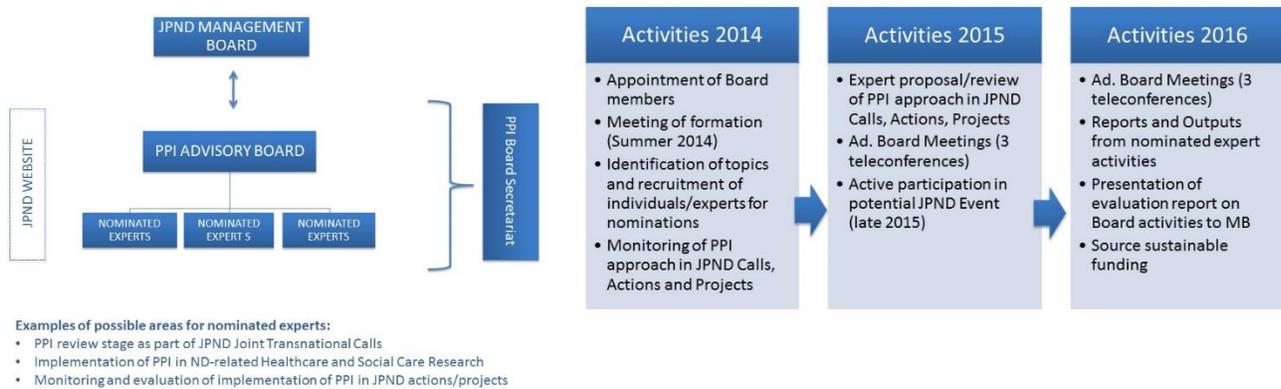
#### IV. MEETING FREQUENCY

The Advisory Board will work together primarily by digital communication (email + teleconferences), with a structured 1.5 hour teleconference approximately every 10-12 weeks, starting from June 2014. The teleconferences will be thematic in nature with 1-2 topics being discussed at each meeting. All Board members will be required to participate and comment, with one presenter per teleconference. The Board shall meet for a one-day physical meeting once per year in accordance with the adopted JPND Work Programme. The dates of the meetings shall be included in the work programme of JPND.

#### V. FUNDING AND DURATION

Under the Work Programme of JPND, it is recommended that an appropriate level of support should be allocated for PPI activities, on a 3-year basis, with an official review process after the three-year period. It is important to ensure that the Board allows patient/academic partners to participate in Board activities without incurring financial burdens.

Following the successful population of the PPI Board in summer 2014, the following timescale has been proposed and accepted by board members:



#### VI. RULES OF PROCEDURE

##### 1. Responsibilities of PPI Stakeholder Board

- According to the Work Programme and Budget handed down by the MB of JPND, identify areas of action and nominate experts for relevant tasks, based on the identified areas of action. The nominated experts

will either undertake the identified areas of work directly or monitor work to be conducted through in-kind contributions from their institutions/organisations, or by outside actors, as appropriate.

- Adopt such rules, regulations and policies as may be required for the sound management of the board.
- Monitor annual progress of relevant tasks. The Board should also develop an indicative program of work and budget for the following two years. The Board may, by consensus, suggest adjustments to the Work Programme and the Budget through the SC of JPND.

## 2. Responsibilities of Chairperson

The Board will have one Chairperson who is responsible for the efficient conduct of the business of the Board and shall in particular:

- Plan the work of the Board together with the JPND Senior Communications Manager / JPND Secretariat.
- Monitor, together with the Senior Communications Manager JPND Secretariat, that the rules of procedure are respected.
- Ensure that at the beginning of each meeting any potential conflict of interest is declared regarding any particular item to be discussed by the Board.
- Aim to achieve consensus on issues discussed by the Board.
- Decide in exceptional cases, when a vote is necessary.
- Co-ordinate the work of the Board with that of other relevant action groups and committees of JPND.
- Ensure that the activities of the Board are reported to the MB or other JPND committees as appropriate.

## 3. Responsibilities of PPI Board secretariat

Under the authority of the Board Chairperson, the secretariat should provide coordination, scientific and administrative support to the Board:

- Provide technical and scientific support to nominated experts, and other members of the Board.
- Prepare and co-ordinate the work of the Board in consultation with the Chairperson.
- Organize meetings of the Board, ensuring timely circulation of meeting documents.
- Ensure adequate co-ordination of the work carried out within the Board and other JPND Action Groups.
- Prepare the agenda and minutes of the meetings of Board in consultation with the Chairperson.
- Communicate when necessary any JPND recommendations relevant to the Board to interested parties.
- Contribute to the identification of experts.

### Current Members of JPND Patient and Public Involvement (PPI) Stakeholder Advisory Board

Name	Role/Experience	Organisation
Marco Blom	Research Manager / Deputy Director of Alzheimer Netherlands with 17 years' experience. Experience in NL with the involvement of people with dementia and carers in research studies. Board member on Dutch Deltaplan for dementia; Founding member of Alzheimer Europe; member of ADI Task force on Scientific Research – links to G8 summit. Alzheimer Netherlands has their own SRA	Alzheimer Netherlands

	which, like JPND, involved a public consultation on priorities.	
<b>Lilly Cappeletti</b>	Associate Director, Research Partnerships, including clinical trial recruitment strategies, such as recruitment and retention planning for the PPMI study and managing Fox Trial Finder.	Michael J Fox Foundation for Parkinson's Research, USA
<b>Simon Denegri</b>	Two national roles in the UK: Chair of INVOLVE and National Director for promotion of PPI. Has been involved in many of the legislative/policy changes to put research/PPI more centre-stage within the NHS/NIHR. Started his PPI career in the Alzheimer's Society over 20 years ago.	National institute for Health Research (NIHR), UK
<b>Florence Pasquier</b>	<p>Professor of neurology. M.D., Ph.D. (in cognitive neuropsychology). 30 years' experience of running a memory clinic in Lille, France, offering knowledge, best care and technology to all, not just university hospitals.</p> <p>Leads a research team entitled "vascular and degenerative cognitive impairment". Involved in clinical research on cognitive and behavioral disturbances. Important collaborations on imaging, epidemiology, and basic research.</p> <p>In process of developing a clinical research team, which has PPI as a priority – providing culturally-sensitive information to explain importance of PPI in research (brain, blood donation, cohort participation, biobanking)</p>	Lille University Hospital, France
<b>Martin Rossor*</b>	<p>Professor of Clinical Neurology at UCL and Honorary Consultant Neurologist at the National Hospital for Neurology. Director of the National Institute of Health Research (NIHR) Clinical Research Network for Dementias and Neurodegenerative Diseases (DeNDroN) and the NIHR Queen Square Dementia Biomedical Research Unit. Recently appointed as the new NIHR National Director for Dementia Research.</p> <p>DenDroN has a strong mandate for patient and public engagement and involvement within the NIHR &amp; NHS. Martin was involved in the JPND SRA consultation with patient organisations and public questionnaire. He is also</p>	DenDroN, UK

	involved with the UK national association of neurologists, bringing patient engagement onto their agenda.	
<b>Päivi Topo</b>	Director of The Age Institute, Finland. Medical Sociologist with a research focus on patient perspective in dementia care. Background in social science and focused on quality of care, assisted living technologies, particularly in dementia & carers. Involved in the national dementia plan for Finland.	The Age Institute, Finland
<b>Rosário Zincke dos Reis</b>	A lawyer, especially interested in legal rights, incapacity, guardianship and many other legal issues related to people with dementia. Involved in EU projects coordinated by Alzheimer Europe.	Alzheimer Portugal

*\*JPND SAB member. Further SAB members may be co-opted for some teleconferences*