

Call for Proposals for  
**"Working Groups to Inform Cohort Studies  
in Neurodegenerative Disease Research"**

**Submission deadline for proposals: 16<sup>th</sup> June 2014**

For further information, please visit us on the web

<http://www.neurodegenerationresearch.eu/>

or contact

**Dr Stephen Meader**

Phone: +44 (0)1793 416419

E-mail: [jpndworkinggroups@headoffice.mrc.ac.uk](mailto:jpndworkinggroups@headoffice.mrc.ac.uk)

**The trans-national 28-member state Joint Programme – Neurodegenerative Disease Research (JPND) is the largest global research initiative aimed at tackling the challenge of neurodegenerative disease (ND). JPND is pleased to launch a rapid-action call for leading scientists in the field to establish working groups to enhance the use of existing longitudinal cohort studies for neurodegenerative disease research.**

**The working groups will be community-led and will establish ‘best practice’ guidelines and/or methodological frameworks to overcome barriers to ND research in population studies and ND-related cohorts. Supported groups will provide outputs within a 6 month timeframe that will be of value to the broader ND research community. These will be made available through the JPND website.**

### **1. Background to the call**

Current population and disease-focused cohorts offer a significant opportunity for advancing our understanding of the risks of developing neurodegenerative conditions and the influences on disease progression. Such cohorts also offer the prospect of providing platforms for prevention and intervention studies in the longer term.

As identified in the recently published report of the [JPND Action Group on Longitudinal Cohort studies in ND research](#), a number of methodological challenges remain if such resources are to be fully exploited. For example, linkage across cohorts would achieve added value, primarily through large increases in sample size and hence the statistical power to look at interactions, although the heterogeneity of studies and measures will require new conceptual approaches if data is to be effectively pooled. Similarly, if the coordination of datasets and/or bioresources is to be promoted across studies, minimum parameters should be defined regarding future data collection, use, and dissemination.

The above report identified a number of areas where further thinking is specifically needed to provide the necessary consensus and framework to support future studies of impact for the field. These were:

- assessing the presymptomatic stages of ND, where new methodological approaches, tools and measures are required.
- the development of standards to support brain imaging, where guidelines are needed to frame future multimodal imaging approaches and perspectives in molecular imaging.
- measurement of cognitive, behavioural and functional changes of relevance to ND progression and outcome, where a consensus on the methodologies to be used is needed.
- data handling, where the emergence of 'omics' technologies requires new approaches to data integration and the interrogation and accessibility of big data sets.
- cohort alignment: in depth work is needed to identify where cohorts can be brought together in selected areas, with concurrent work on how data pooling can realistically be achieved.
- clinical data linkage: an assessment is needed of how studies with clear clinical linkage might be exploited in prospective studies, such that study harmonisation might be achieved, with the identification of best practice for of data protection, storage and dissemination solutions.
- the potential for exploiting intervention-studies of potential risk factors where ND is not the primary focus (e.g. clinical trials in hypertension, diabetes etc.), to ascertain how they could be used to adequately address risk of ND as an outcome.

JPND has decided that these issues can be progressed most effectively through assembling motivated groups of leading experts in the ND field. Accordingly community-led Working Groups are to be supported that can push forward the conceptualization of such topics in order to provide guidelines

and/or best practice frameworks of value to the wider research community.

## **2. Focus of the call**

To establish a number of JPND-sponsored expert Working Groups to address issues of key relevance for the future development of cross-centre cohort studies. These should address the key methodological challenges that need to be addressed if cohort studies are to be fully exploited for ND research.

Areas to be considered are highlighted above, although other topics that are similar in theme may be proposed. However these areas need to be relevant to longitudinal population studies and disease related cohorts and applicants are advised to contact the [UK secretariat](#) to discuss eligibility well before the submission date.

## **3. Characteristics and mode of operation of Working Groups**

- Involve key opinion leaders with an internationally competitive track record in ND research. The core will be drawn from within JPND member countries, however the inclusion of experts from other countries beyond JPND is encouraged
- Led by an individual with the energy and commitment to drive a collaborative and output-directed process. This individual will not necessarily be the most senior person in the group
- Guided by a clear project plan
- A typical arrangement would entail small workshops at the beginning and end of the process, with sub groups established to achieve more focused work through remote-working
- Consideration should be given to establishing an external reference group to ensure that objectivity is maintained in developing the Working Group's conclusions and recommendations

## **4. Funds available and form of support**

Up to 450,000 € will be available to fund Working Groups under this call. Funding decisions will be based on the quality of the applications received and the best fit to the call. As the Working Groups will be expected to deliver reports of wide applicability to the field of ND research, only one activity will be funded in any topic area. Delivery of the reports to the JPND Secretariat must be by March 2015.

Each working group can bid up to 50,000 € for support of its activities, which are expected to run for a maximum of 6 months.

- Funding will cover the costs of meetings and travel required to deliver the Working Groups' objectives
- It is expected the budget will allow for two small workshops, with further work to be undertaken through email, tele-, video- or web-conferencing.

This funding will not provide support for:

- direct research activity or equipment;
- the salaries of tenured investigators, although funds to support an administrative co-ordinator for the activity will be permitted;
- student stipends.

## 5. Eligibility

- Applications are to be led by a coordinator from an eligible institution within one of the participating JPND member countries (in accordance with the Terms and Conditions of the relevant national funding organisations).
- As a cross-JPND activity experts from all JPND member countries may participate in Working Groups, including countries who are not financial participants to the call. In addition Working Groups are encouraged to include key expertise from non-JPND countries.
- The JPND countries contributing funding to this call are:
  - Denmark, Danish Strategic Research Council
  - Canada, Canadian Institutes of Health Research (*\*joined on May 28<sup>th</sup>, 2014 – country-specific requirements apply – available at link below*)
  - France, French National Research Agency
  - Germany, Federal Ministry of Education and Research
  - Italy, Ministry of Health
  - Luxemburg, National Research Fund
  - The Netherlands, The Netherlands Organisation for Health Research and Development
  - Norway, The Research Council of Norway
  - Sweden, The Swedish Research Council for Health, Working Life and Welfare
  - United Kingdom, Medical Research Council
- Only trans-national research groupings will be funded. To qualify for funding, each proposal must involve research experts from three or more of the 28 JPND countries.
- Working Group contributors are permitted to be members of Working Groups in more than one proposal. However, it is recommended that individuals do not act as the Working Group Coordinator for more than one proposal.
- Where there is overlap between Working Groups for closely related yet complementary proposals, these will be assessed separately.
- The best proposals and funding priorities will be identified following assessment, as detailed in section 8.
- Following the review, a JPND Sponsor Group will align working groups with the funding available. There will be the flexibility to do this because groups are expected to have members from at least three and probably many more countries.

## 6. Outputs

Working Groups are required to produce a report at the end of the funding period that contains guidelines or a methodological framework, to be published on the JPND website. This report is expected to act as a reference point for the wider ND research community in planning/delivering future research studies. Applicants should also put forward an appropriate plan to disseminate the outcomes, for example, through publication in a journal.

## 7. Applications

The application form for this call is available at the link below:

<http://www.neurodegenerationresearch.eu/initiatives/jpnd-alignment-actions/longitudinal-cohorts/call-for-working-groups>

Applicants will be required to cover the following:

- the rationale for the proposed study, identifying the research need being addressed, and why the outputs (whether guidelines or a methodological framework) will uniquely contribute to moving ND research forward;
- the objectives and mode of operation of the Working Group, specifying the work-plan and timeline for delivery;
- the identity of the experts to be involved, specifying the leadership /coordinator for the exercise;
- where appropriate, the identity of experts who will act as an advisory reference group for the process to help validate the outputs;
- a breakdown of the budget request;
- project plan with expected outcomes and deliverables, including dissemination.

Applicants are required to submit their proposals using the Application Form provided. Application forms should be emailed in pdf format to [jpndworkinggroups@headoffice.mrc.ac.uk](mailto:jpndworkinggroups@headoffice.mrc.ac.uk) with "JPND WG Application" as the subject line; **the deadline for receipt of applications is 17.00h (GMT+1, BST) on Monday 16<sup>th</sup> June 2014.**

#### **8. Assessment Criteria**

Applications will be assessed by a review group based upon the JPND Scientific Advisory Board (SAB) in July 2014. The SAB may draw on additional external advice as required. Applications will be assessed on the following criteria:

- The scientific fit to the call
- The standing of the experts within the proposed working group and whether as a group they have the appropriate mix of scientific skills
- The timeliness of the ideas proposed for discussion
- Plans for dissemination and the potential impact of the outcomes to the field
- The feasibility of the project plan to include delivery of the report in Q1 2015

#### **9. Enquiries**

For any enquiries please contact Dr Stephen Meader:  
[jpndworkinggroups@headoffice.mrc.ac.uk](mailto:jpndworkinggroups@headoffice.mrc.ac.uk) or **+44 (0)1793 416419**