JPND Call for Proposals:

"European research projects for the evaluation of health care policies, strategies and interventions for Neurodegenerative Diseases"

Submission deadline for proposals: 21st March 2013

Proposal template

Electronic proposal submission

For further information, please visit us on the web

http://www.neurodegenerationresearch.eu/

or contact

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1. Introduction

Neurodegenerative diseases (ND) are debilitating and largely untreatable conditions that are strongly linked with age and lead to disability and reduced health related quality of life (HRQoL). Amongst these disorders, the dementias are responsible for the greatest burden of disease, with Alzheimer's disease and related disorders affecting some 7 million people in Europe, and this figure is expected to double every 20 years as the population ages. In addition to the heavy burden put on the patients, the relatives and carers, the total direct and informal care costs of Alzheimer's and related disorders across Europe are in the order of €130 billion per year, highlighting age-related neurodegenerative diseases as one of the leading medical and societal challenges faced by our society. In this context, the 'Joint Programme Neurodegenerative Disease Research' (JPND) has been established (http://www.neurodegenerationresearch.eu) in order to better coordinate European efforts on the level of transnational collaboration and project coordination on the basis of the JPND European Research Strategy released in February 2012.

A lot of diversity and heterogeneity currently exists among different health care and social care systems related to neurodegenerative diseases between and within individual JPND participating countries. In general, there is inefficient and inequitable coordination between healthcare and social care systems, and often inequitable access to care. There is an immediate need to better understand existing systems as the basis for successive initiatives tackling health and social care systems with respect to neurodegenerative diseases. This understanding can be achieved by charting, analysis and evaluation of the strengths and weaknesses of formal and informal care pathways, health and social care policies and strategies across countries by means of transnational research projects. Additionally, in order to benefit persons with neurodegenerative diseases and their carers in the shorter term, there is a need for research on the most appropriate health and social care interventions. Benchmarking healthcare and social care systems in terms of

cost effectiveness, HRQoL infrastructures and interventions will provide a hitherto unavailable knowledge base, more transparency and is expected to lead to improved policy options.

The following funding organisations have agreed to fund a joint call for transnational research projects in this scientific area, with a view to adding value to their existing nationally funded activities. The call will be conducted simultaneously by the funding organisations in their respective countries and coordinated centrally by the Joint Call Secretariat (JCS).

- **Belgium, Agency for Innovation by Science and Technology, Flanders region**
- **Denmark, The Danish Strategic Research Council**
- **France, French National Research Agency**
- **Germany, Federal Ministry of Education and Research**
- **Ireland, Health Research Board**
- **Israel, Chief Scientist Office, Ministry of Health**
- **Italy**
    - **Ministry of Health**
    - **Ministry of Education, Universities and Research**
- **Luxembourg, National Research Fund**
- **Netherlands, The Netherlands Organisation for Health Research and Development**
- **Norway, The Research Council of Norway**
- **Poland, National Centre for Research and Development**
- **Portugal, Portuguese Foundation for Science and Technology**
- **Sweden, Swedish Research Council**
- **United Kingdom, Economic and Social Research Council.**

2. Aim of the call

Through JPND, this joint transnational call is being launched to support appropriate approaches to understanding health care policies, strategies and interventions. The aim of the call is to assess and compare pathways to care, through evaluating access to, the quality and the cost effectiveness of care provision and support for patients with neurodegenerative diseases across different care settings. Research will be supported which addresses the levels of both health / social care delivery at the macro level (system and infrastructures) and at the individual level of persons with ND and their carers. Proposals may include research based evaluation of

interventions relevant for those with ND. Where appropriate, proposals should include validation and improvement of outcome measures that are relevant for persons with ND and their carers in order to provide reliable tools for measurements of health related quality of life (HRQoL).

Scope of call: Applications with relevance for the following neurodegenerative diseases can be included in the call:

- **Alzheimer's disease and other dementias**
- **Parkinson's disease and PD-related disorders**
- **Prion disease**
- **Motor neuron diseases**
- **Huntington's disease**
- **Spinocerebellar ataxia (SCA)**
- **Spinal muscular atrophy (SMA).**

Studies primarily relevant to other diseases with a neurodegenerative component are not included in the call. Applicants should consider whether and how the results of their research can be generalised beyond the condition or intervention under investigation.

Proposals should contain appropriate as well as innovative approaches and methodologies combined with well-structured work plans and clearly defined goals deliverable within three years. Multidisciplinary research approaches are encouraged. Applicants should consider the ways in which socio-economic factors, as well as issues such as gender or comorbidities, should be taken into account. JPND encourages public and user involvement, for example with consumers or patient advocacy groups, in the project, where such involvement is aimed at improving research and protocol design or usability of the project and its findings. The added value to ongoing activities and the impact on treatment, health / social care management or delivery for those with neurodegenerative diseases across countries should be explained.

Applicants should clearly demonstrate that they have the range of skills required to conduct the study or that appropriate collaborations are in place, while a plan for managing the consortium should also be provided. The investigators must be able to demonstrate access to relevant population groups or database material as appropriate. Pooling and synergistic usage of existing data, studies, and/or patient cohorts, are encouraged, where appropriate.

Proposals submitted under the call of evaluating health care policies, strategies and interventions in the area of neurodegenerative diseases should address one or more of the following aspects:

- Research-based analysis and evaluation of healthcare and/or social care pathways for patients with ND and their families across different countries

- Research-based analysis and evaluation of educational programmes for patients, carers and staff (voluntary as well as professional) in healthcare and social care systems and related support measures
- Research-based analysis and evaluation of end-of-life strategies in different countries relevant to ND
- Research-based analysis and evaluation of psychosocial interventions relevant for patients with ND, or their carers, such as coping strategies and skills, aimed at maximising the ability and wellbeing of persons with ND
- Research-based analysis and evaluation of existing assessment tools and clinical and health related quality of life (HRQoL) outcome measures for persons with ND
- Cost effectiveness studies of healthcare interventions across different countries
- Research on the implementation of positively evaluated strategies, interventions and measures.

To have impact at a European level, it is expected that all proposals will link activities across eligible research organisation within JPND member countries. .Proposals are encouraged to import expertise from areas outside of neurodegeneration research. There should be **clear added value** provided through the collaboration.

Training and mobility of early-stage researchers (e.g., researcher exchanges for students and postdoctoral researchers with the aim of learning new research approaches) within the consortia are encouraged.

3. Application

3.1 Eligibility

Joint transnational research proposals may be submitted by research groups working in universities (or other higher education institutions), non-university public research institutes, health and social care service settings, hospitals, as well as commercial companies, in particular small and medium-size enterprises. The eligibility of the afore-mentioned institutions, together with details of eligible costs (personnel, material, consumables, equipment, travel money, etc.), are subject to the individual administrative requirements of individual funding organisations and may therefore vary. Clarification about funding rules has to be obtained from the individual funding organisations (see contact details of participating organisations in the annex below).

Each proposal must involve **a minimum of three and a maximum of eight (3-8) JPND-funded research groups**. Only transnational projects will be funded; each consortium must involve groups from at least three different countries of the funding organisations participating in this call (see list above). Research groups from countries that are not partners in the JPND may participate in

projects if they are able to secure their own funding. They must state clearly in the proposal if these funds are already secured or if not, how they plan to obtain funding in advance of the project start. However, the majority of research groups in a consortium and the coordinator must be from countries of the JTC partner organisations.

Each consortium should have the critical mass to achieve the research aims and **should clearly demonstrate added value** from working together. The project coordinator will be responsible for its internal scientific management and will represent the consortium externally.

Whilst applications will be submitted jointly by groups from different countries, individual research groups will be funded by the individual JPND funding organisation(s) of their respective country/region. Eligibility criteria are the matter of individual partner organisations (see contact details in the annex below).

Please note that the inclusion of a non-eligible partner (i.e., an applicant applying for funding, although this partner cannot be funded by the funding agency in its country for administrative reasons according to country specific regulations) in a proposal may result in the rejection of the entire proposal without further review. Applicants are therefore strongly advised to contact their national/regional funding organisation and confirm eligibility before participating in an application (see country specific information on the JPND website (http://www.neurodegenerationresearch.eu

3.2 Financial and legal modalities

Projects can be funded for a period of up to three years. Single research groups will be funded according to national regulations of the funding organisations. Eligible costs may vary according to the corresponding funding organisation´s regulations. Each group is subject to the rules and regulations of its respective national/regional funding organisation.

A project consortium agreement must be signed by all project partners in each project consortium. The project consortium agreement will specify at least management, decision making, monitoring, reporting, intellectual property rights (IPR) issues. Administrative and funding arrangements will be stated in the project consortium agreement as a bilateral responsibility between each project partner and the relevant funding organisation.

3.3 Submission of joint transnational proposals

One joint transnational proposal document (in English) shall be prepared by the consortium partners and must be submitted to the Joint Call Secretariat (JCS) by the co-ordinator. A proposal template is available at the JPND website (http://www.neurodegenerationresearch.eu).

Adhering to this template is absolutely required. Individual funding organisations will receive copies of this proposal from the JCS. Proposals must be received (uploaded) **no later than March 21, 2013** via the **electronic submission system** (https://www.pt-it.de/ptoutline/application/JPND_HC).

3.4 Further information

For further details, please refer to the respective submission forms ("Proposal template") available at the JPND website (http://www.neurodegenerationresearch.eu)..

If you need additional information, please contact the Joint Call Secretariat or your funding organisation's representative (see annex for contact details).

4. Evaluation and decision

4.1 Formal check of proposals

The Joint Call Secretariat (JCS) will check proposals to ensure that they meet the call's formal conditions (date of submission; number of participating countries; inclusion of all necessary information in English). In parallel, the JCS will forward the proposals to the national/regional funding organisations which will perform a check of compliance with their respective regulations. Proposals not meeting the formal conditions will be rejected. Proposals passing these checks will be forwarded to the joint Peer Review Panel (PRP) for evaluation.

4.2 Peer-review of proposals

The reviewers will carry out the evaluation according to the following evaluation criteria, which are equally weighted:

1. Relevance to the aim(s) of the call
2. Scientific quality of the proposal, including appropriate methodology and level of originality, and feasibility of the project (adequacy of project work plan, time schedule, access to patient groups or data (as appropriate), quality and linkages of data within and between countries, budgetary and other resources)
3. Competitiveness of participating research groups in the field(s) of the proposal (expertise relevant for the field, expertise of the research groups), and their appropriate mix; quality of collaborative interaction between the groups for the proposed work, level of training/knowledge exchange between research organisations, and added value, on both scientific and transnational levels, of the research consortium
4. Deliverable outcomes in the short, medium and long term and likely impact - potential of the expected results to impact on policy and practice, connection with relevant stakeholders in policy / practice.

4.3 Decision

The international joint Peer Review Panel will use a scoring system to establish a threshold above which projects will be fundable in principle. A ranking list will be prepared for those proposals scoring above the fundable level, based on scientific peer review assessment. The final ranking will also take into account the optimal portfolio spread that will provide most benefit (i.e., funding may be restricted to only the best application where there are two or more proposals of similar scope and of similar high scientific quality). Based on these recommendations, final decisions will be made by the funding organisations, which will be responsible for the final contributions to these projects being subject to their predetermined budget limits.

5. Funding procedure / Responsibilities / Reporting requirements

Projects can be funded for a period of up to three years and according to funding organisations' regulations. Funding is expected to start at the end of 2013 or beginning of 2014.

The research groups of successful collaborative projects will be funded directly by the respective funding organisations.

Funding will be administered according to the terms and conditions of the responsible funding organisations, taking into account all other applicable regulations and legal frameworks.

Each project must nominate a project coordinator, who represents the consortium externally and is responsible for its internal management towards the JPND (such as monitoring, reporting, intellectual property rights (IPR) issues). Within a joint proposal, each group leader will be the contact person for the relevant national/regional funding organization.

The project coordinator will be required to submit a brief annual scientific progress report on the joint project, on behalf of the project consortium, to the Joint Call Secretariat (JCS) in January of each year. The project coordinator will be required to submit a final scientific progress report on the joint project, on behalf of the project consortium, to the Joint Call Secretariat (JCS) within 3 months after the project end. It may also be necessary for group leaders to submit reports individually to their funding body should it be required. Funding recipients must ensure that all outcomes (publications, etc.) of transnational JPND projects include a proper acknowledgement of JPND and the respective funding partner organisations.

Annex

Please note that country specific requirements might apply to this call. For further information, please contact your national representative:

Country	Contact officer	Funding organisation, contact details
Belgium	Mr. Olivier Boehme Mr. Paul Schreurs	Research Foundation – Flanders (FWO) olivier.boehme@fwo.be +32 (0)2 550 1545 Agency for Innovation by Science and Technology (IWT) PS@iwt.be + 32 (0)2 432 42 85 http://www.iwt.be/
Denmark	Prof. Dr. Mogens Hørder	The Danish Strategic Research Council (DSF) mhorder@health.sdu.dk +45 6550 3015; mobile +45 6011 3015
France	Dr. Natalia Martin	French National Research Agency (ANR) Health & Biology Department natalia.martin@agencerecherche.fr + 33 1 73 54 81 33 http://www.agence-nationale-recherche.fr/en/
Germany	Dr. Constanze Hahn Dr. Rainer Girgenrath	Programme Management Agency (PT-DLR) – Health Research, on behalf of the Federal Ministry of Education and Research (BMBF) Constanze.Hahn@DLR.de +49 228 3821 1865 www.gesundheitsforschung-bmbf.de Programme Management Agency (PT-DLR) – Health Research, on behalf of the Federal Ministry of Education and Research (BMBF) Rainer.Girgenrath@DLR.de +49 228 3821 1200 www.gesundheitsforschung-bmbf.de
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Italy	Dr. Gaetano Guglielmi	Ministry of Health (MOH) and Ministry of Education, Universities and Research (MIUR) g.guglielmi@sanita.it +39 0659942186 http://www.salute.gov.it/
Luxembourg	Dr. Frank Glod	National Research Fund (FNR) +352 261925 33 frank.glod@fnr.lu www.fnr.lu
The Netherlands	Dr. Edvard Beem	The Netherlands Organisation for Health Research and Development (ZonMw) Beem@zonmw.nl + 31 70 3495104 www.zonmw.nl

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Portugal	Ms. Ana Quartin	Portuguese Foundation for Science and Technology (FCT) ana.quartin@fct.pt +351 21 391 1542 www.fct.pt
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