



JPND
research

EU Joint Programme – Neurodegenerative Disease Research

JPND Call for Proposals:
**"Multinational research projects on Health
and Social Care for Neurodegenerative
Diseases"**

Submission deadline for pre-proposals:

March 6, 2018, 23:59h C.E.T.

For further information, please visit us on the web

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

or contact the JPND Joint Call Secretariat:

Sabrina Voß

(+49) 228-3821 1821 or sabrina.voss@dlr.de

Olaf Krüger

(+49) 228-3821 1296 or olaf.krueger@dlr.de

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1. Introduction

Neurodegenerative diseases are debilitating and largely untreatable conditions that are strongly linked with age. Worldwide, there are estimated to be 47 million people suffering from Alzheimer's disease and related disorders, the most common class of neurodegenerative diseases. This figure is expected to double every 20 years as the population ages. The total direct and informal care costs of Alzheimer's, Parkinson's and related disorders are in the range of €105-160 billion per year across the European Union and about US\$ one trillion worldwide. Existing treatments for neurodegenerative diseases are limited in effect and mainly address the symptoms rather than the cause or the progressive course. In addition, providing appropriate health and social care represents an increasing responsibility for people who live with neurodegenerative diseases, relatives and carers that urgently need to be addressed. In this context, the EU Joint Programme on Neurodegenerative Disease Research (JPND) was established in order to better coordinate research efforts across countries and disciplines to more rapidly find causes, develop cures and identify better ways to care for people with neurodegenerative disease. The JPND Research and Innovation Strategy, published in 2012 and refreshed in 2017, identified research priorities and provided a framework for future investment.

Recent developments indicate a shift towards living better with neurodegenerative diseases. Novel health and social care concepts focus on what people still can contribute in the context of the disease and how their environment may influence this process. This includes preserving dignity, independence and social participation and reducing excess disability in each stage of the disease. However, the availability and quality of health and social care services for individuals with neurodegenerative diseases, their carers and families vary considerably across Europe and beyond. In general, co-ordination between health care and social care systems is often inefficient and access to care is inequitable. A better understanding of the factors that contribute to social inclusion, civic participation, dignity and quality of life for patients and their families is essential. In addition, there is need to identify and overcome barriers to the adoption of novel, evidence-based health promotion strategies in order to reduce the impact of disease.

The funding organisations that have agreed to fund this joint call for multinational research projects, with a view to adding value to their existing nationally funded activities, are listed below. The call will be conducted simultaneously by the funding organisations in their respective countries and coordinated centrally by the Joint Call Secretariat.

- **Australia, National Health and Medical Research Council**
- **Belgium, Research Foundation Flanders**
- **Canada, Canadian Institutes of Health Research**
- **Czech Republic, Ministry of Education, Youth and Sports**
- **Denmark, Innovation Fund Denmark**
- **Finland, Academy of Finland**
- **France, French National Research Agency**
- **Germany, Federal Ministry of Education and Research**
- **Ireland, Health Research Board**
- **Italy, Ministry of Education, Universities and Research**
- **Italy, Ministry of Health**
- **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**
- **Slovakia, Ministry of Education, Science, Research and Sport of the Slovak Republic**
- **Spain, National Institute of Health Carlos III**
- **Sweden, Swedish Research Council for Health, Working Life and Welfare**
- **Switzerland, Swiss National Science Foundation**
- **Turkey, Scientific and Technological Research Council of Turkey**
- **United Kingdom, UK Alzheimer's Society**

2. Aim of the call

The aim of the call is to establish a limited number of ambitious, innovative, multi-national and multi-disciplinary collaborative research projects that address health and social care delivery at the macro level (system and infrastructures) as well as (at) the individual level of patients, their carers and families. Evaluating the strengths and weaknesses of formal and informal care approaches and existing infrastructures is a prelude to implementing improved, evidence-based approaches and thereby improving the quality of life for those affected by neurodegenerative diseases and the quality of care.

Most health and healthcare research would be impossible without the active involvement of patients. Thus, JPND has determined that Patient and Public Involvement (PPI) should be an integrated part of the implementation of its Research and Innovation Strategy. Proposals to be funded under this call will therefore need adequately to involve patients, carers and the public. Consortia are expected to make every effort to include PPI approaches, where appropriate, at each stage of the research process including the preparation of the application (see the JPND website for further information). In the application it must be described in which step of the research process patient or relatives will be, or already are, involved and which roles they would play. If possible, patient representatives

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should be consulted from each of the countries that participate in the consortium. If a PPI approach is not fitted, this must be justified.

Proposals on health and social care can apply to patients with any or several of the following neurodegenerative diseases:

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

Proposals submitted under this call will include, but are not limited to, the research areas listed below. Proposals can focus on one or several of these areas:

- **Care pathways and services using the potential of patient involvement**
Among others, benefits and harms of advance care planning and the ethical issues involved; identification of transitions along the disease trajectory in terms of quality of life and carers’ capacity to provide support, including support from civic voluntary carers; observational studies of needs, strengths, preferences and values of people affected by disease and carers including knowledge about suicidal behavioral and risk of suicide among patients; individualisation of supporting technologies to reflect and respond to the enormous heterogeneity of need, abilities and preferences of patients and carers.
- **Factors influencing progression and prognosis of disease**
Among others, interplay of social factors in combination with economic, cultural, environmental and biological factors in the determination of cognitive decline, behavioral and psychological symptoms, self-estimation of coping, well-being and disease progression, quality of life; repurposing of data available through existing cohorts to adopt and integrate new procedures to study the interplay of social factors in combination with economic, environmental and biological factors and changes over time; prevention of incriminating consequences of disease including the influence of social responses to disease progression and symptoms.
- **Outcome measures for patients and their informal carers**
Among others, measures (identification) of effective factors emphasizing positive outcomes such as autonomy, protection, resilience, dignity, opportunity for reciprocity, use of cognitive reserve and health-related quality of life and broader well-being to better reflect individual strengths and aspirations throughout the entire course of the disease from first symptoms to end of life.

– **Palliative care of patients**

Among others, development, investigation and implementation of global quality indicators on palliative care while considering barriers and facilitators in providing care and utilising indicators; identification of the end-of-life phase and use of advance care planning to improve the quality of life and the quality of dying.

– **Cost-effectiveness and affordability of interventions including ethical concerns**

Among others, equity of access to and the effectiveness and cost-effectiveness of pathways to prevention, diagnosis, treatment, care, follow-up and support across countries; transferability of current hospice care models into social care situations and the ethical issues involved.

Proposals should have novel, ambitious aims and ideas combined with well-structured work plans and clearly defined objectives deliverable within three years. Each consortium should have the critical mass to achieve ambitious scientific goals and outline the added value of working together. Applicants should demonstrate that they have the expertise and range of skills required to conduct the study or that appropriate collaborations are in place. The added value to ongoing activities and the expected impact on future health and social care for people suffering from neurodegenerative diseases should be explicitly stated.

Appropriate access to and synergistic usage of resources, e.g. data from patients and health care providers, existing population and disease-specific cohorts and registries or connections to health records, is expected. Data, tools and resources being generated within the research projects should be made widely available to the public domain, taking into account legal and ethical requirements, to increase their added value. Access must be provided to other bona fide research groups. Consortia are strongly advised to define arrangements to deal with this issue across countries, while preserving integrity of study subjects.

Proposals should address socio-economic factors, gender-related research questions and comorbidities, where appropriate. Consortia should incorporate these factors when formulating their research hypotheses, aims and work plans. Considering cross-cultural issues and diversity, particularly when developing and implementing instruments and intervention strategies, should be ensured across research efforts.

Training of young researchers and mobility (e.g., researcher exchanges for students and postdoctoral researchers) within the consortia are encouraged, where this can be specifically justified in terms of the training opportunities provided to the individual and the needs of the field. Please note that there may be restrictions according to national regulations. To have an impact at European and partner country levels, it is expected that all proposals will link activities across laboratories/clinics/care settings within JPND member countries. Proposals are encouraged to import expertise from areas outside of neurodegeneration research, e. g. from primary care, memory units or sentinel networks, which can bring innovation to the approach to be pursued. The case must be made for the added value that will be provided by the collaboration on a multidisciplinary level.

3. Management of the call

Below we outline the role of the three bodies that are responsible for the management of the call and the evaluation of proposals. Any person being involved in one of these bodies will not be allowed to submit or participate in proposals within this call.

- The Joint Call Secretariat is led by DLR-PT, Health Research, Germany. The Joint Call Secretariat is responsible for the management of the call. It is a point of contact for both applicants and partner organisations.
- The Call Steering Committee is composed of representatives from each participating funding organisation. All decisions concerning the call procedures will be taken by the Call Steering Committee. Based on scientific recommendations from the Peer Review Panel and budget considerations it will confirm the list of consortia that will be invited to submit full proposals and also confirm final funding recommendations to the national/regional funding organisations.
- The Peer Review Panel is composed of internationally recognised scientific experts from different fields of research related to the topics of the call. The Peer Review Panel is responsible for the scientific evaluation of proposals at both the pre- and full proposal stage. The Peer Review Panel will rank the proposals according to the evaluation criteria and make funding recommendations to the Call Steering Committee.

4. Eligibility

Joint transnational research proposals can be funded for a period of up to three years. They may be submitted by research groups working in universities (or other higher education institutions), non-university public research institutes, hospitals and other health and social care settings, as well as commercial companies, in particular small and medium-size enterprises. Specific regulations of individual funding organisation might apply and must be taken into account.

Consortia may consist of partners who receive funding for research under this award (regular funded partners) as well as non-funded external collaborators. Regular partners are represented by individual research groups (typically headed by a principal investigator or a young academic group leader) within individual institutions. Each regular partner must request funding by one of the funding organisations participating in the call (see section one). If different research groups from the same institution request funding, they must be counted as individual regular partners.

Each proposal must involve a minimum of three and a maximum of six regular partners from at least three different countries participating in this call (see section one). If the proposal involves at least one regular partner from an underrepresented European country (Czech Republic, Poland, Slovakia), the maximum number of regular partners is extended to seven partners. For reasons of transnational balance, no more than two regular partners from the same country are allowed to join a proposal.

In addition, external collaborators (e.g., research groups from countries that are not participating in this call or research groups that do not apply for funding) may participate in proposals. External

collaborators must be able to secure their own funding. They must state in the proposal if these funds are already secured or, if not, how they plan to obtain funding in advance of the project start.

Whilst proposals are to be submitted jointly by research groups from different countries, individual regular partners will be funded by the corresponding funding organisation participating in this call. In consequence, eligibility for funding is decided by the respective funding organisations and details of what may or may not be funded are subject to the specific regulations of these funding organisations and thus may vary.

Information on specific regulations (e.g., additional forms to be submitted before the submission deadline or details on eligible costs) is provided in the specific information sheets. Nevertheless, applicants are strongly advised to contact their corresponding funding organisation to confirm their eligibility and to gain latest information. The inclusion of a regular partner not being eligible for funding may result in the rejection of the entire proposal without further review.

5. Application

There will be a two-stage procedure for applications: pre-proposals and full proposals. The revision of the proposals between these stages will be accepted in the circumstances indicated below. At both stages, one joint proposal document shall be prepared by the consortium and submitted by the co-ordinator. In addition, some funding organisations are requesting additional information to be submitted before the proposal submission (see specific information sheets). In case of any questions concerning the proposal submission, please contact the Joint Call Secretariat.

5.1 Pre-proposal submission

Pre-proposals must be submitted by the co-ordinator in electronic format no later than 23:59h C.E.T. **on March 6, 2018**, via the JPND **electronic submission system**. No other means of submission will be accepted. A pre-proposal template is available at the JPND website. Adhering to this template is mandatory.

5.2 Revision of proposals

A revision of proposals is allowed after the pre-proposal evaluation. However, it is restricted to those consortia explicitly selected for the full proposal stage. The following modifications are permitted in the preparation of a full proposal:

- Including or replacing of regular partners. This should normally be restricted to one regular partner and the following cases:
 - Where a regular partner from the pre-proposal has been declared non-eligible.
 - Where the modification is derived and justified from the pre-proposal evaluation.
 - Where the aim is, based on a scientific justification, to include a regular partner from an underrepresented European country (Czech Republic, Poland, Slovakia).
- Including or excluding external collaborators (no further restrictions).
- Changing the work plan and/or the budget of regular partners where it is either derived from the pre-proposal evaluation or the modification of the consortium (as outlined above). Any

changes need to be well justified in the full proposal. Changes to the budget of individual regular partners require approval by the respective funding organisation.

Applicants are responsible for ensuring that any changes applied during the revision are in line with the eligibility criteria of the call (see section four). Full proposals that exceed the above conditions for revision or doesn't meet the eligibility criteria of the call may be rejected without further review. Therefore, applicants are strongly advised to consult the Joint Call Secretariat and/or the funding organisations involved in the full proposal in advance of the submission.

5.3 Full proposal submission

Full proposals will be accepted only from those consortia explicitly invited by the Joint Call Secretariat to submit them. They must be submitted by the co-ordinator in electronic format no later than 23:59h C.E.T. **on June 27, 2018**, via the **electronic submission system**. No other means of submission will be accepted. The Joint Call Secretariat will provide a full proposal template and further information to the co-ordinator. Adhering to this template is mandatory. Any changes applied during the revision should be described and justified in the full proposal.

6. Evaluation and decision

6.1 Evaluation criteria and scoring

The Peer Review Panel will carry out the evaluation of pre-proposals and full proposals. The following evaluation criteria will be applied:

- **Relevance** to the aim of the call.
- **Scientific quality** including level of innovation, originality, feasibility and risk analysis.
- **Transnational added value** from working together as a research consortium.
- **International competitiveness** of participating research groups and their appropriate mix.
- **Deliverable outcomes** in the short, medium and long term including potential foreseen impact for innovation in Health and/or Social Care and provided plans for implementation.

6.2 Evaluation and decision on pre-proposals

The Joint Call Secretariat will check the pre-proposals to ensure that they meet the call's formal conditions. In parallel, the involved funding organisations will check for compliance with their funding regulations. Pre-proposals not meeting the formal or eligibility criteria will be rejected.

Pre-proposals passing the formal and eligibility check will be evaluated by the Peer Review Panel. At least three panel members will be asked to assess each pre-proposal on a written basis. Afterwards, a subset of the Peer Review Panel will meet in-person to discuss evaluations, where needed, and to jointly recommend pre-proposals to be invited to the full proposal stage. Based on these recommendations, the Call Steering Committee will make a final decision on full proposal invitations.

The Joint Call Secretariat will inform each co-ordinator about the outcome of the pre-proposal evaluation and provide the written evaluations (with the evaluators remaining anonymous), the recommendation of the Peer Review Panel and the decision of the Call Steering Committee.

6.3 Evaluation and decision on full proposals

Full proposals will be checked regarding formal and eligibility criteria and evaluated by the Peer Review Panel as described in section 6.2. The Peer Review Panel will make funding recommendations for each full proposal and agree on a ranking order based on the scientific assessment according to the evaluation criteria. Based on these recommendations and on available funds, the Call Steering Committee will propose a package of awards for a final decision by the respective funding organisations, subject to budgetary considerations.

The Joint Call Secretariat will inform each co-ordinator about the outcome of the full proposal evaluation, thereby providing the written evaluations (with the evaluators remaining anonymous), a summary of the panel discussion, the recommendation of the Peer Review Panel and the final decision of the funding organisations.

7. Funding regulations, responsibilities and reporting requirements

Funding decisions will be made on a national basis by the relevant funding organisations and administered according to their terms and conditions, taking into account all other applicable regulations and legal frameworks.

A consortium agreement signed by all regular partners of the proposal is a requirement for the liberation of funds. It will specify as a minimum: decision making, monitoring, reporting, intellectual property rights management and sharing of data and resources, as appropriate. Administrative and funding arrangements will be stated in the consortium agreement to be a bilateral responsibility between each regular partner and the relevant funding organisation.

Each consortium must nominate a co-ordinator, who represents the consortium externally, acts as first point of contact and is responsible for its internal management in terms of formal responsibilities towards JPND (such as monitoring, reporting, intellectual property rights issues and sharing of data and resources). The co-ordinator will be required to submit a brief annual scientific progress report in January of each year and a final scientific progress report within three months of the end of the project to the Joint Call Secretariat. Those reports may internally be used for monitoring and evaluation purposes to assess the progress of the implementation of JPNDs' Research and Innovation Strategy. Each group leader individually will also be the contact person for the relevant funding organisations. It may be necessary for group leaders to submit additional reports to their funding organisation, if required.

Funding recipients must ensure that all outcomes (publications, etc.) of transnational JPND projects and all other communications include a proper acknowledgement both of JPND and the respective funding organisations. For this purpose, a JPND dissemination strategy has been agreed to by all JPND member states. Adhering to the JPND dissemination guidelines is mandatory for researchers funded under the umbrella of JPND. From time to time consortia will be asked to work with the JPND Communications Manager and the funders on related communications (e.g., for the JPND website, blogs, tweets).

8. Contact details

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

Country	Funding organisation, contact details
Australia	National Health and Medical Research Council (NHMRC) Julie Glover +61 2 6217 9451 or dementia.research@nhmrc.gov.au
Belgium	Research Foundation Flanders (FWO) Alain Deleener or Toon Monbaliu +32 2 550 15 95 or +32 2 550 15 70 or eranet@fwo.be
Canada	Canadian Institutes of Health Research (CIHR) Melody Sajedi +1 613 960 9475 or melody.sajedi@cihr-irsc.gc.ca Flamine Alary +1 613 960 9475 or flamine.alary@criugm.qc.ca
Czech Republic	Ministry of Education, Youth and Sports (MSMT) Department of Research and Development Daniel Hanšpach +420 234 811 360 or Daniel.Hanspach@msmt.cz
Denmark	Innovation Fund Denmark (IFD) Mogens Horder +45 66502820 or MHorder@health.sdu.dk
Finland	Academy of Finland (AKA) Sirpa Nuotio +358 295 33 5082 or sirpa.nuotio@aka.fi
France	French National Research Agency (ANR) Sheyla Mejia-Gervacio +33 178 09 80 14 or sheyla.mejia@agencerecherche.fr
Germany	Federal Ministry of Education and Research, supported by DLR-PT Sabrina Voß +49 228 3821 1821 or sabrina.voss@dlr.de Olaf Krüger +49 228 3821 1296 or olaf.krueger@dlr.de
Ireland	Caitriona Creely +353 1 2345 204 or ccreely@hrb.ie
Italy	Ministry of Education, Universities and Research (MIUR) Aldo Covello +39 06 5849 6465 or aldo.covello@miur.it Valeria Cardia +39 06 5849 7333 or valeria.cardia@miur.it

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Italy	Ministry of Health (MoH-IT) Giselda Scalera Jose Ruiz Alvarez Maria Grazia Mancini +39 06 59943214 3215 or research.eu.dgric@sanita.it
Luxembourg	National Research Fund (FNR) Frank Glod +352 261925 33 or frank.glod@fnr.lu
Netherlands	Netherlands Organisation for Health Research and Development (ZonMw) Marjolein Scholten +31 70 349 53 35 or Scholten@zonmw.nl
Norway	Research Council of Norway (RCN) Alexandra Bjørk- Skaflestad +47 22037224 or alb@forskningsradet.no
Poland	National Centre for Research and Development (NCBR) Marcin Chmielewski +48 22 39 07 109 or marcin.chmielewski@ncbr.gov.pl
Slovakia	Ministry of Education, Science, Research and Sport of the Slovak Republic (MESR) Ms. Lubica Pitlova +4212 59374741 or lubica.pitlova@minedu.sk
Spain	National Institute of Health Carlos III (ISCIII) Mauricio Garcia-Franco +34 91 822 2885 or mauriciog@isciii.es
Sweden	Swedish Research Council for Health, Working Life and Welfare (Forte) Peter Allebeck +46 8 775 40 93 or Peter.Allebeck@forte.se
Switzerland	Swiss National Science Foundation (SNSF), Division Biology & Medicine Claudia Ellenrieder +41 31 308 22 73 or claudia.ellenrieder@snf.ch
Turkey	Scientific and Technological Research Council of Turkey (TÜBİTAK) Gaye CETINKAYA CAMPARI +90 312 298 17 91 or gaye.cetinkaya@tubitak.gov.tr
United Kingdom	UK Alzheimer's Society Katherine Gray Katherine.Gray@alzheimers.org.uk or research@alzheimers.org.uk