

EU Joint Programme - Neurodegenerative Disease Research (JPND)

Call for expert Working Groups:

"The impact of COVID-19 on Neurodegenerative Diseases research"

Submission deadline for proposals: December 14, 2021, 12:00h C.E.T.

For further information, please visit us on the web http://www.ipnd.eu/

or contact the JPND Joint Call Secretariat: (+49) 228 3821 2111 or ipnd@dlr.de

PREAMBLE

The EU Joint Programme - Neurodegenerative Disease Research (JPND) is the largest global research initiative aimed at tackling the challenges of neurodegenerative diseases. JPND is pleased to launch a rapid-action call for leading scientists in the field to establish Working Groups dedicated to the <u>conceptualization</u> of the call topic. The Working Groups should discuss innovative and new ideas and meet for one or two small workshops. They must provide outputs of value to the broader research community, e.g. by establishing best-practice guidelines and/or methodological frameworks.

However, the call does not support direct research activities and studies.

1. INTRODUCTION

Neurodegenerative diseases are debilitating and largely untreatable conditions that are strongly linked with age. Worldwide, there are estimated to be 50 million people with Alzheimer's disease and related disorders, the most common group 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 expected to surpass €350 billion per year across the European Union. Existing treatments for neurodegenerative diseases are limited in effect and mainly address the symptoms rather than the cause or the progressive course.

In this context, the <u>EU Joint Programme - Neurodegenerative Disease Research</u> (JPND) has been established 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 diseases. To identify research priorities, the JPND <u>Research and Innovation Strategy</u>, published in 2019, provides a framework for future investment.

The COVID-19 pandemic has had a major impact on almost all aspects of our life and will most likely result in major long-lasting changes in the future. These changes include how research on neurodegenerative disease is conducted during and after the pandemic. Patients with neurodegenerative disease are among the most vulnerable to COVID-19 infections and the measures of social distancing and quarantine. Further it is unknown how COVID-19 infections and its long-term effects might influence the later development and progression of neurodegenerative diseases. On the other hand, the COVID19 pandemic may offer a unique opportunity to better understand important aspects of neurodegenerative diseases and accelerate innovations that can be beneficial for research and the care of patients with neurodegenerative diseases.

2. AIM OF THE CALL

The aim of the call is to establish a number of ambitious, innovative, multi-disciplinary and multi-national expert Working Groups to discuss research strategies that concern the impact of COVID-19 on the development and progression of neurodegenerative disease as well as on the care of patients with neurodegenerative diseases. These strategies can also consider the impact of COVID-19 on neurodegenerative disease research itself, how it is conducted and how it influenced technological innovations for neurodegenerative diseases. Furthermore, they can explore methods and sources of data to enable or improve the surveillance of the impacts of COVID-19 as they relate to the development or progression of neurodegenerative diseases.

Working Groups must focus on one 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)

Working Groups are to be research community-led and must demonstrate a clear scientific benefit from working across national borders. They should aim at pushing forward the conceptualization of such topics and envisage the provision of best-practice guidelines as well as methodological frameworks of value to the wider research community. Working Groups may focus on one or several of the following research areas (non-limitative list):

- Understanding the short- and long-term consequences of viral (especially SARS-Cov2) infections on the brain that relate to the susceptibility for the development and the progression of neurodegenerative diseases;
- Analyzing similarities between viral functioning and mechanisms related to neurodegeneration, e.g. on the level of protein aggregation and neuroinflammation;
- Investigating the impact of social isolation, anxiety and social distancing on loneliness, cognition and the course of neurodegenerative diseases;
- Studying the relation between social functioning, cognitive functioning and immune system, including the impact of post-COVID symptoms;
- Analyzing how pandemic conditions affected access to health and social care and rehabilitation for patients with neurodegenerative diseases;
- Developing innovative data collection, monitoring, and surveillance methods to gather and share population-based evidence on the interconnections between COVID-19 and neurodegenerative diseases that supports future research, public health actions, and health care planning;
- Assessing technological innovations for remote data capture including cognitive assessments or the use of portable devices for monitoring motor, sensory and behavioral and social functions, that might be developed at an accelerated speed due to the pandemic;
- Developing programs that promote the use of remote technologies including educational programs for researchers and patients.

Patient related research as envisaged by this call benefits from the active involvement of the persons concerned. Thus, Working Groups need to adequately involve patients, their relatives and carers and the public (see the JPND website <u>Public and Patient Involvement – PPI</u> for further information). This relates to the planning stage during the application as well as the later work developed by the postulating group. In the application it must be described how patients, their relatives and carers are involved and from where they are recruited. If such an approach is missing it must be well justified.

3. ELIGIBILITY AND MODE OF OPERATION

The funding organisations participating to this call that have agreed to provide financial support for Working Groups are listed below:

- Belgium, The Research Foundation Flanders (FWO)
- Canada, Canadian Institutes of Health Research (CIHR)
- France, French National Research Agency (ANR)
- Germany, Federal Ministry of Education and Research (BMBF)
- Italy, Ministry of Health (IT-MOH)
- Luxembourg, National Research Fund (FNR)
- Norway, The Research Council of Norway (RCN)

- The Netherlands Organisation for Health Research and Development (ZonMw)
- Sweden, Swedish Research Council for Health, Working Life and Welfare (FORTE)
- Medical Research Council (MRC), part of UK Research and Innovation

A Working Group must be led by a coordinator from an institution being eligible for one of the participating funding organisations listed above. Information on eligibility of institutions and expenses can be obtained directly from the respective funding organisation (contact details see section 8). The coordinator assembles the Working Group, act as first point of contact and is responsible for the internal management (such as monitoring, reporting, intellectual property rights issues and sharing of data).

The coordinator may nominate experts from any country worldwide to join the Working Group, including countries who are not financially participating to the call. Working Groups are encouraged to include key expertise from non-JPND countries, where relevant. However, at least half of the participants of the Working Group must be affiliated to institutions within JPND countries (Albania, Australia, Austria, Belgium, Bulgaria, Canada, Croatia, Czech Republic, Denmark, Finland, France, Germany, Greece, Hungary, Ireland, Israel, Italy, Luxembourg, Netherlands, Norway, Poland, Portugal, Romania, Slovak Republic, Slovenia, Spain, Sweden, Switzerland, Turkey and United Kingdom).

Only transnational Working Groups are funded. A minimum of six experts, including the coordinator, from at least three different countries must be involved in a Working Group, which should ideally not exceed 25 participants. Experts may join multiple Working Groups; however, they must not act as the coordinator of more than one Working Group.

Each Working Group can bid up to 50.000 € (plus institutional overhead) for support of its activities, which should normally not exceed a time period of 9 months. A usual 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. A joint workshop of all funded Working Groups may be envisaged at the end of the funding period. Participation of all the funded project coordinators as a result of this call in the final workshop will be mandatory

Funding may be used to conduct the workshops (e.g. costs related to accommodation and catering or temporary student staff) and to compensate for travel costs of the participants. It may also be used to utilize remote working (e.g. costs for tele-conferencing) as well as data exchange, harmonisation and dissemination. No funding is provided for direct research activities (e.g. costs for research equipment, salaries of investigators or scientific staff as well as student stipends).

4. APPLICATION

The coordinator must submit a joint proposal on behalf of the entire Working Group via the JPND electronic <u>submission and evaluation system</u> no later than 12:00h C.E.T. on December 14, 2021. Using the <u>proposal template</u> provided at the JPND website is mandatory. No other ways of submission are accepted.

5. EVALUATION AND DECISION

Detailed information on the evaluation and decision-making process can be obtained from the accompanying <u>call procedures</u> document. All submitted proposals are checked to ensure that they meet the formal conditions as well as the specific eligibility criteria of the participating funding organisations. Proposals that successfully pass these checks are assigned to peer-review. At least three international and independent peer-reviewers evaluate each eligible proposal according to the following criteria:

- Scientific fit to the topic of the call
- Relevance and likely impact of the activity
- Involved expertise and their appropriate mix
- Potential outcomes and plans for dissemination

Based on the written evaluations, the funding organisations take final funding decisions. It is their goal to maximise the number of high-quality Working Groups to be supported through this call. The coordinators receive written information about the outcome of the evaluation and the final funding decision in June 2022. The working groups are expected to start their activities as of the second half of 2022.

6. AWARDS

Each selected Working Group receives financial support from one of the funding organisations participating to this call. The award must be used to compensate for the expenses of the entire group and is typically provided to the coordinator. Awards are made according to the funding organisations' specific terms and conditions, thereby taking all applicable regulations and legal frameworks into account. Consequently, details of what may or may not be funded are subject to the specific regulations of the respective funding organisation and may therefore vary.

7. EXPECTED OUTPUTS

Working Groups are required to produce a report at the end of the funding period to be published on the JPND website. Reports should contain guidelines or a methodological framework and are expected to act as a reference points for the wider research community in planning and delivering future studies. Working Groups should also put forward an appropriate plan for wide disseminate their outcomes, for example, through publication in a scientific journal, conferences and publication on relevant websites. It must be ensured that all outcomes include a proper acknowledgement of JPND and the respective funding organisations. For this purpose, a JPND <u>dissemination strategy</u> has been agreed upon, which can be downloaded from the <u>JPND website</u>.

8. CONTACT DETAILS

The Joint Call Secretariat is the central point of contact for general call-related questions. The funding organisations provide additional information on eligibility and their specific regulations.

General questions and guidance	
JPND	Joint Call Secretariat Sabrina Voß / Katrin Michel: +49 22838212111 or jpnd@dlr.de
Country specific aspects and eligibility	
Belgium	Research Foundation Flanders (FWO) Toon Monbaliu, +32 25 50 15 70 or eranet@fwo.be
Canada	Canadian Institutes of Health Research (CIHR) David Coffey, +1 343-552-2712 or David.coffey@cihr-irsc.gc.ca Flamine Alary, +1 613 96 09 475 or flamine.alary@criugm.qc.ca
France	French National Research Agency (ANR) Sheyla Meija-Gervacio, +33 178 09 80 14 or sheyla.mejia@agencere-cherche.fr
Germany	Federal Ministry of Education and Research, supported by DLR-PT Sabrina Voß, +49 228 38 21 -2111 or ipnd@dlr.de
Italy	Ministry of Health (MOH-IT) Giselda Scalera, research.EU.dgric@sanita.it Maria Josefina Ruiz Alvarez, +39 06 59 94 32 14 Maria Grazia Mancini, +39 06 59 94 32 15
Luxembourg	National Research Fund (FNR) Sean Sapcariu, +352 26 19 25 33 or sean.sapcariu@fnr.lu
Norway	Research Council of Norway (RCN) Alexandra Bjørk- Skaflestad, +47 22 03 72 24 or alb@forskningsradet.no
The Nether- lands	Netherlands Organisation for Health Research and Development (ZonMw) Marjolein Scholten, +31 70 34 95 335 or Scholten@zonmw.nl
Sweden	Swedish Research Council for Health, Working Life and Welfare (Forte) Teresia Weinberg, +46 (0)8-562 051 72or teresia.weinberg@forte.se
UK	Medical Research Council (MRC), part of UK Research and Innovation Clara Fons, clara.fons@mrc.ukri.org