

EU Joint Programme - Neurodegenerative Disease Research (JPND)

## **Call for expert Working Groups:**

**"Concepts for health and social care research for neurodegenerative diseases"**

Submission deadline for proposals:  
**December 13, 2022, 12:00h C.E.T.**

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

or contact the JPND Joint Call Secretariat:  
**(+49) 228 3821 2111 or [jpnd@dlr.de](mailto:jpnd@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 conceptualization 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 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.

In this context, the [EU Joint Programme - Neurodegenerative Disease Research](#) (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 [Research and Innovation Strategy](#), published in 2019, provides a framework for future investment.

While there have been developments towards living better with neurodegenerative diseases, most available interventions and support are intended for patients who are newly diagnosed. There still is a relative lack of research and supply for patients, particularly at moderate, advanced and end of life stages of disease progression. Affected people face a reduced ability to manage daily-life challenges along with a loss of independency, social participation and dignity. In addition, they often suffer from social isolation and restrictions regarding personal support as a consequence of the still ongoing pandemic. The factors that contribute to social inclusion, civic participation, dignity and quality of life for these patients and their families are not fully understood. In consequence, the supply offered by the health care systems of individual countries, if any, does not adequately meet the needs of patients. Furthermore, the availability of and the access to support varies considerably across Europe and beyond and there is inefficient and inequitable coordination between health and social care systems. Deeper analysis of the strengths and weaknesses of existing supply, the social factors contributing to cognitive decline or stability as well as new concepts and ideas for enhancing health and social care are therefore needed in order to assess the problems and needs of patients, carers and relatives.

## 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 and align the specific needs of patients and currently available supply by the health and social care system, thereby outlining strategies to improve support for people particularly at moderate, advanced and end of life stages of disease progression.

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 and in particular bringing scientific communities with different expertise to work together. 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. The approaches should be integrative (clinical, epidemiological, social, legal) and have a strong focus on patient involvement throughout the planning and conduction of the project. Disability, gender and cultural aspects should be integrated, where possible.

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 for [further information](#)). This relates to the planning stage during the application as well as the later work of the panel. In the application it must be described how patients, their relatives and carers are involved and from where they are recruited.

### **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:

- **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)**
- **Ireland, Health Research Board (HRB)**
- **Netherlands, The Netherlands Organisation for Health Research and Dev. (ZonMw)**
- **Norway, The Research Council of Norway (RCN)**
- **Sweden, Swedish Research Council for Health, Working Life and Welfare (FORTE)**

A Working Group must be led by a coordinator from an institution being eligible for one of the participating funding organisations. 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, acts 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 Working Group may include experts from any country worldwide, including countries who are not financially participating to the call. In order to gain a wider perspective, Working Groups are encouraged to include expertise from partners established in European countries with a less advanced scientific community on health and social care research, where relevant. However, at least half of the participants of the Working Group must be from 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 five different countries must be involved in a Working Group, which should 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 12 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 is 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 and 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 [submission and evaluation system](#) no later than 12:00h C.E.T. on December 13, 2022. Using the [proposal template](#) 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 [call procedures](#) 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 on a remote basis 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 2023. The working groups are expected to start their activities as of the second half of 2023.

#### **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. Additional deliverables (such as a Data management plan, or Consortium agreement) may be requested subject to the funding organisation's Terms and Conditions.

#### **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 dissemination of their outcomes, for example, through publication in a scientific journal. It must be ensured that all outcomes include a proper acknowledgement of JPND and the respective funding organisations. For this purpose, a JPND [dissemination strategy](#) has been agreed upon, which can be downloaded from the [JPND website](#).

## 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.

<b>General questions and guidance</b>	
<b>JPND</b>	Joint Call Secretariat, Sabrina Voß, <a href="mailto:jpnd@dlr.de">jpnd@dlr.de</a>
<b>Country specific aspects and eligibility</b>	
<b>Canada</b>	Canadian Institutes of Health Research David Coffey <a href="mailto:david.coffey@cihr-irsc.gc.ca">david.coffey@cihr-irsc.gc.ca</a>
<b>France</b>	French National Research Agency Sheyla Mejia-Gervacio +33 178 09 80 14 or <a href="mailto:sheyla.mejia@agencerecherche.fr">sheyla.mejia@agencerecherche.fr</a>
<b>Germany</b>	DLR Project Management Agency Sabrina Voß +49 228 38 21 2111 or <a href="mailto:jpnd@dlr.de">jpnd@dlr.de</a>
<b>Italy</b>	Ministry of Health (IT-MOH) Chiara Ciccarelli <a href="mailto:c.ciccarelli@sanita.it">c.ciccarelli@sanita.it</a> Simona Bifulchi <a href="mailto:s.bifulchi@sanita.it">s.bifulchi@sanita.it</a>
<b>Ireland</b>	Health Research Board (HRB) Siobhán Hackett <a href="mailto:shackett@hrb.ie">shackett@hrb.ie</a>
<b>Norway</b>	The Research Council of Norway Alexandra Bjørk- Skaflestad +47 22 03 72 24 or <a href="mailto:alb@forskningsradet.no">alb@forskningsradet.no</a>
<b>Sweden</b>	Swedish Research Council for Health, Working Life and Welfare (Forte) Teresia Weinberg <a href="mailto:Teresia.Weinberg@forte.se">Teresia.Weinberg@forte.se</a>