

EU Joint Programme - Neurodegenerative Disease Research (JPND)

Call for expert Working Groups:

"Use of digital technologies in neurodegenerative disease research and clinical practice"

Submission deadline for proposals: **December 12, 2023, 12:00h C.E.T.**

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

or contact the JPND Joint Call Secretariat: (+49) 228 3821 2111 or 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 this networking activity 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 JPND and the broader research community by delivering a report at the end of the funding period.

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

1. INTRODUCTION

Neurodegenerative diseases are debilitating conditions that are strongly linked with age. Worldwide, there are estimated to be more than 50 million people living with 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. With no causative treatment being available today, neurodegenerative diseases have high personal, societal and economic impact.

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.

Digital technologies have taken a central position in peoples' everyday lives, e.g. by managing daily routines, offering timely information and navigation or allowing boundless communication. They have also made their way into health and social care research and practice, e.g. by offering automated data processing and analysis, algorithms facilitating human efforts or tracking people's health and physical status. Beside the impressive features offered already today, technological advancements are rapid and temporarily erratic, e.g. with regard to the conceivable roll-out of virtual reality and artificial intelligence. Assessing the impact of such cutting-edge technologies on health and social care research and services often generates a high level of uncertainty. In addition, the fast progression makes it complicated to implement them in research and in the care of patients. However, both fields may potentially benefit from making use of cutting-edge digital technologies. This specifically relates to neurodegenerative diseases, where patients require enhanced levels of support and scientists strive to unravel the functioning of the brain, which is the most complex organ in the human body. The use of advanced digital technologies for the diagnosis, disease modelling, treatment and care has the potential to improve life for people with neurodegenerative diseases.

2. AIM OF THE CALL

The aim of the call is to establish a number of ambitious, innovative, multi-disciplinary and multinational expert Working Groups to assess the current and future impact of digital technologies on research and care in the field of neurodegenerative diseases. In pursuit of this aim, Working Groups may address the following aspects:

- Identification of the most relevant technologies, their current and potential use as well as their impact on the field in the next decade,
- Outlining the gaps, barriers and hurdles and opportunities in research in order to improve the use of specific digital technologies in the future for the diagnosis and treatment of ND,
- Analyzing the risks and opportunities that go along with an advanced use of specific digital technologies,
- Ethical considerations with a focus on the perspective of patients, relatives and carers (please refer to: https://legalinstruments.oecd.org/en/instruments/OECD-LEGAL-0457).

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 areas of expertise together to work collaboratively. The approaches should be integrative (e.g. involve clinicians, engineers, physicists, computer scientists, mathematicians and non-medical personnel as well as, legal, technological and social experts) and include disability, gender, ethic, socioeconomic and cultural aspects, where possible. Experts' discussion is envisaged to identify the appropriate developments specific for the field while involving experts from outside the boundaries of the neurodegenerative disease field.

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 <u>further information</u>). This relates to the planning stage during the application as well as the later work of the panel. Applications must describe how patients, their relatives and carers are involved and from where they are recruited.

3. 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 reference points for the wider research community in planning and delivering future studies. In addition, Working Groups are encouraged to share their thoughts on future developments and relevant research questions to be tackled in the future. Working Groups should also put forward an appropriate plan for wide dissemination of their outcomes, for example, through publication in a scientific journal. All outputs must 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>.

4. ELIGIBILITY AND MODE OF OPERATION

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

- France, French National Research Agency (ANR)
- Germany, Federal Ministry of Education and Research (BMBF)
- Ireland, Health Research Board (HRB)
- Italy, Ministry of Health (IT-MOH)
- Netherlands, The Netherlands Organisation for Health Research and Dev. (ZonMW)
- Norway, The Research Council of Norway (RCN)
- United Kingdom, Medical Research Council (MRC) as part of UK Research and Innovation (UKRI)

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 in section 8). The coordinator assembles the Working Group, acts as first point of contact and is responsible for the 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 in 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 well-established scientific community in 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 $50.000 \in$ (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 as well as data exchange and harmonisation and dissemination. No funding is provided for direct research activities (e.g. salaries of scientific staff).

5. 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 12, 2023. Using the <u>proposal template</u> provided at the JPND website is mandatory. No other ways of submission are accepted.

6. 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 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, including diversity in gender, geographic and seniority
- Potential outcomes and plans for dissemination, including a focus on open science and open access

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 2024. The working groups are expected to start their activities as of the second half of 2024.

7. 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.

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 and Sara Breid jpnd@dlr.de
Country specific aspects and eligibility	
France	French National Research Agency Sheyla Meija-Gervacio +33 178 09 80 14 or sheyla.mejia@agencerecherche.fr
Germany	DLR Project Management Agency Sabrina Voß and Sara Breid +49 228 38 21 2111 or jpnd@dlr.de
Ireland	Health Research Board (HRB) Siobhán Hackett Amanda Daly eujointprogrammes@hrb.ie
Italy	Ministry of Health Chiara Ciccarelli c.ciccarelli@sanita.it Simona Bifolchi s.bifolchi@sanita.it
Netherlands	The Netherlands Organisation for Health Research and Dev. Rosalie Nelissen +31703495439 or nelissen@zonmw.nl
Norway	Research Council of Norway (RCN) Alexandra Bjørk- Skaflestad +47 22 03 72 24 or alb@forskningsradet.no
United Kingdom	Medical Research Council (MRC) as part of UK Research and Innovation (UKRI) Siv Vingill siv.vingill@mrc.ukri.org