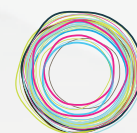


JPND Research and Innovation Strategy

Executive Summary



Tackling the challenge of Alzheimer's
and other neurodegenerative diseases
in Europe and beyond



JPND
research

EU Joint Programme – Neurodegenerative Disease Research

The full JPND Research and Innovation Strategy including Annexes, can be viewed and downloaded [here](#)

Cover photo credit within 'JPND domains' brain image, lower right: Photo by Ewa Jezierska of the JPND-supported project MeetingDem, showing the Meeting Centre in Wrocław, Poland.

Executive Summary

Background and Purpose of the JPND Research and Innovation Strategy

Neurodegenerative diseases (ND) are debilitating and largely untreatable conditions that are strongly linked with age. Amongst these disorders, the dementias are responsible for the greatest burden of global disease, with 50 million people worldwide living with Alzheimer's disease and related disorders. By 2050 in Europe alone, total direct and informal care costs for Alzheimer's and Parkinson's disease are estimated to surpass €350 billion per year, indicating that ND represent one of the leading medical and societal challenges of our time.

JPND is a major collaborative research initiative established to tackle the problems posed by ND and to accelerate progress in the search for solutions. JPND aims to align and build upon national programmes to increase impact and effectiveness of research and to identify common goals that would benefit from joint action. This Research and Innovation Strategy represents a framework for future implementation and investment that addresses how the global research effort can most effectively be harnessed to improve prevention, diagnosis, treatment and patient care for these debilitating conditions.

Scientific Priorities

To achieve impact will require encouragement of novel as well as multidisciplinary approaches. There is a need to strengthen and extend existing capabilities across the full spectrum of basic, clinical, health and social care, and translational research. Research will need to take account of gender and sex-related differences and to consider their relevance across all domains. JPND has identified the following thematic priorities for future research:

» The origins and progression of neurodegenerative disease

A major challenge is to improve knowledge about the causes and progression of ND and the factors that determine a person's risk and resilience. Efforts to identify the origins of ND should place greater emphasis

on understanding disease phenotypes within the broader scientific and life course context and gaining insights from a wider range of relevant diseases. The significance of recently discovered risk factors needs to be determined and research is required to identify new genetic, epigenetic, environmental and social modulators. A better appreciation is needed of the role of ageing in chronic disease and the relationship to ND development and resilience.

» Disease mechanisms and models

A more complete understanding of the underlying disease mechanisms is required to underpin the development of new diagnostic and therapeutic approaches and identify appropriate time windows for intervention. Success in this area will require novel and improved existing animal and cellular models of ND, taking advantage of insights from human experimental medicine. Greater emphasis should be placed on reverse translation from ND patients to develop more predictive models and on research to determine the role of new pathways in ND pathogenesis.

» Diagnosis, prognosis and disease definitions

Standard clinical assessments fail to capture the evolving complexity of ND, necessitating refinement and updating of current diagnostic criteria. The various forms and subtypes of ND require better definition in both 'presymptomatic' and 'symptomatic' states, given that abnormal processes underlying these disorders occur many years before the onset of clinical disease. New or improved diagnostic tools and identification of novel biomarkers are required to enable earlier, and more accurate detection or diagnosis of ND, including the ability to predict disease outcome and progression and monitor the impact of therapies and interventions. Standardisation and harmonisation across such tools and assessments will be critical to ensure the comparability of results and to support cross-centre studies.

» Developing therapies, preventive strategies and interventions

To advance the field and transform treatment and care for people with ND requires work on a range of fronts and a willingness to embrace innovative

approaches. This may include a combination of strategies at different intervention time points, including multi-drug therapies, technological and social interventions, together with lifestyle modifications and care approaches. Further research on preventive strategies and interventions will help to lessen the risk of developing ND or help promote the capacity of the brain to resist neurodegeneration. To accelerate translation of basic findings to clinical benefit, the validity of model systems used for target identification and therapeutic development needs improvement. Longer-term approaches should be pursued, that promote regenerative strategies and develop novel systems for drug delivery and targeting to specific sites in the brain and nervous system.

» Health and social care

In general, there is inefficient and inequitable co-ordination between healthcare and social care systems in individual countries. Research should employ conceptually sound approaches to understand the factors that contribute to social inclusion, civic participation, dignity, health-related quality of life (QoL) and wellbeing for individuals with ND and their families. It is crucial for findings to be validated in real world settings, taking account of acceptability, cost-effectiveness and the complex ethical issues relating to ND care. A patient-centred approach to care should be adopted, with appreciation of the various factors that affect the rate of clinical progression. Assisted living technologies may help address the needs of individual patients with ND and their carers in both early and moderate disease stages, in effective, cost-effective and equitable ways. Further research should also be undertaken to inform palliative and end-of-life care.

Enabling Activities

A number of cross-cutting activities will be needed to progress the scientific themes outlined above:

» Supportive infrastructure and platforms

In seeking to create an enabling environment for ND research, there is a need to encourage integration and harmonisation of data and materials, and to promote

an open-access approach to sharing and pooling of data and resources. The ability to do this is aided by recent advances in informatics and artificial intelligence (AI) and increasing recognition of the strength of effective research collaboration and partnerships. Standardised methods and tools for data collection and analysis should be adopted for example, to address the requirements of high-throughput technology platforms and biobanking, and to better connect and exploit existing cohorts, patient registers and sample/data collections.

» Partnership with industry and fostering innovation

Many different commercial organisations engage with ND research, ranging from the pharmaceutical, diagnostic, biotechnology, bioinformatics, imaging and digital health sectors, through to assisted living and healthcare providers. Connection between and across academic and industry domains is essential to deliver novel approaches to diagnosis, treatment and care. Innovation should be promoted within a multi-partner international funding framework by fostering a risk-taking approach, encouraging co-development of research across sectors and supporting knowledge transfer and innovation between sectors.

» Working with regulatory organisations

Effective translation of research into meaningful and beneficial treatments for patients requires dialogue and co-operation with key transnational and national regulatory agencies. Greater interaction with regulators should be encouraged, particularly to integrate patient needs at all stages of therapeutic development and to assist the standardisation of procedures around the control and consent of patient data. Regulatory support networks should be promoted to disseminate best practices in regulation, to define typical clinical development and address potential bottlenecks at an early stage.

» International partnership

It is now well recognised that the unmet clinical need and societal impact of ND is a global issue, and opportunities exist for JPND to link to worldwide research efforts in this area. Such co-operation should be strategically directed and offer clear benefit to

JPND's objectives. This includes utilising resources and infrastructure outside of Europe and better connecting global patient public involvement (PPI) and ethics activities.

» Capacity building

Across ND research certain areas lack capacity and need to be strengthened to ensure that future opportunities can be realised. Accordingly, networks should be established across and between disciplines and researchers to bring innovative thinking to the field. Approaches to capacity building already used within JPND countries or internationally should be shared to reveal practices that might be adapted. Areas may include encouraging a culture of open science and improving the quality and capability of AI and digital technologies for use in home monitoring, risk prediction, diagnosis and clinical trials.

» Education and training

There is considerable heterogeneity in awareness amongst clinicians, healthcare professionals and related stakeholder groups about the ways that people are affected by ND. An evidence-led educational approach will help to embed a research culture across the full spectrum of health, social and palliative care and help to promote public health messaging. Recommendations include education and training on the needs of ND patients with specific conditions, the value of research participation and the use of new or existing technologies or devices to promote patient independence.

» Connection to policy makers

JPND provides a single international framework to highlight important current and emerging issues for policy consideration at the national level. Two translational gaps in ND-related policy are to prioritise implementation of new technologies or practices towards those patients and carers who need them the most and to implement research outcomes effectively into public health policy. To enhance the progress made to date and address ongoing challenges, the commitment of national governments to supporting ND research needs to be strengthened and work is needed to better

facilitate the exchange of data, funds and resources across borders.

» Communication and outreach

The research agenda for ND must connect and engage with a wide range of sectors and stakeholders for effective translation into policy and practice. JPND will ensure that all stakeholder communities are well informed about ongoing ND research and its outcomes, increasing awareness and support for ND research among decision makers, patients, carer organisations and the public. This should also help to increase research participation and lower the stigma associated with ND.

Delivery of the Research and Innovation Strategy

This Research and Innovation Strategy provides a framework of opportunities for countries participating within and beyond JPND. Member countries will use it both as the basis for co-operative action that realigns or links national investments for increased impact, and for decisions on the provision of joint funding to support new research of international scientific quality.

Summary

JPND provides a framework to address the major societal challenge of ND, which cannot be resolved through national research programmes alone. This document updates the common vision of 30 JPND member countries, first published in 2012. It provides a strategic approach to support world class research and innovation to promote exploitation of scientific opportunities, confront barriers to progress, and define novel approaches to prevention, intervention and care. The recommendations address the full spectrum of research and associated approaches necessary to achieve impact. JPND is working alongside other stakeholder groups towards delivering this Research and Innovation Strategy. The ultimate goal is to undertake research for translation into new interventions to improve the health and wellbeing of patients with ND, their families and carers, as well as economic and societal benefit in Europe and beyond.

