

Executive Summary JPND Achievements through Internal evaluation

The EU Joint Programme for Neurodegenerative Disease research (JPND) was established in 2009 as the pilot initiative of the Member State led Joint Programming Initiatives (JPIs). It enables participating countries to voluntarily work together on age-related neurodegenerative diseases (ND) through “à la carte” participation suited to each country’s priorities and areas of excellence. JPND promotes the establishment, alignment and progression of national research programmes to increase the effectiveness and impact of research efforts in this field. JPND’s mission is to tackle neurodegeneration through an unprecedented global collaborative research endeavour.

As part of the EU Coordination and Support Action JPsustaiND Work Package (WP) 6 Monitoring, Evaluation and Impact Assessment, ZonMw as WP6 lead performed an internal self-evaluation. JPND’s, in particular JPsustaiND’s, progress (November 2015 - February 2019) was assessed against 2 sets of monitoring indicators: Type A (effect of JPND on research programming, research policy and funding) and Type B (scientific and societal impact of JPND research on ND).

The self-evaluation comprised 5 phases:

- Development of a logic model and evaluation framework (evaluation questions set against indicators).
- Compilation and analysis of existing evidence against the monitoring indicators, drawing on JPND monitoring reports and other available documents e.g. periodic reports JPsustaiND, deliverables JPsustaiND, minutes MB, EB, Excom, NSC meetings etc.
- Desk research:
 - ERA-LEARN survey among project coordinators JPND calls 2011-2013.
 - Development of case studies to illustrate outcomes and impact of some of the JPND-supported projects.
- Development of recommendations for JPND, based on the evidence gathered and reviewed.
- Reporting

The self-evaluation focussed on JPND’s effectiveness in achieving reach and impact through the research and activities it realised.

The self-evaluation was followed by an external evaluation.

JPND/JPsustaiND Achievements

Through a common vision and the alignment of national research programmes supported by an efficient management structure, JPND/JPsustaiND has formalised the achievement of a European Research Area in the field of ND. JPND has implemented a stronger global dimension, increased the multi-annual commitment of its participating countries, and fostered international progress for research and innovation on ND through the development of novel research tools and infrastructures and innovative collaborative research projects. The results of the performance indicators are testimony to the objectives that JPND have achieved.

Involvement of stakeholders

- JPND has brought together funders and policy makers through its internal processes, researchers through its funded projects, and different initiatives in the area of ND through joint activities. Through the MB platform it has provided a common basis for discussion and collaboration among policy makers and funding organisations. The involvement of Scientific Advisory Board, composed of pre-eminent scientists from academic research, industry and patient organisations in the field of ND, ensures the right priority setting for research themes in ND.
- In 2018, JPND counted 30 Member States including 5 associated countries and 2 third countries (Canada and Australia) members.



Quality assurance of JPND

- Quality assurance was maintained from the outset at both the programme and project levels. The content of the programme was continuously monitored and adjusted to meet the needs of involved stakeholders, as well as to respond to new developments in the field of ND.

International progress of JPND research

- JPND Joint Transnational Calls (JTC) for research proposals directly support research projects after a highly competitive selection process. From the start (2011) to date, at least one JTCs was launched per year (11 to date) addressing high priority areas in ND research and focussed on the JPND diseases: Alzheimer’s disease (AD) and other dementias, Parkinson’s disease (PD) and PD-related disorders, Prion disease, Motor neurone diseases (MND), Huntington’s disease (HD), Spinocerebellar ataxia (SCA) and Spinal muscular atrophy (SMA). Two of these calls (in 2015 and 2019) were launched with the EC funding support (ERA-NET cofund).
- The number of research groups applying to the JPND calls has almost doubled (>900) and the number of supported projects has increased by 27,5%.
- The success rate per call was between 5 and 29%.

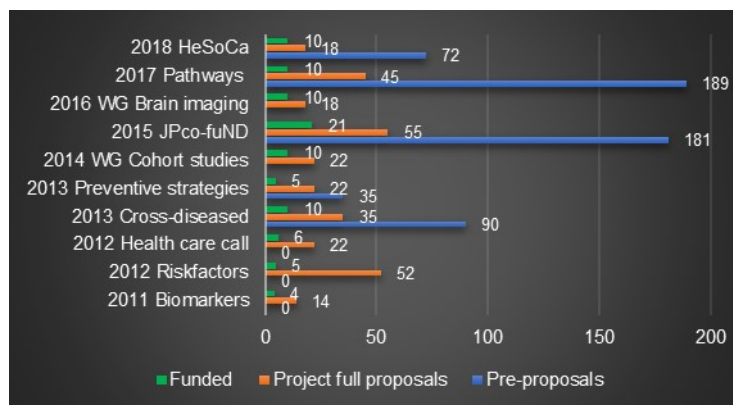


Figure. Submissions received during JPND calls for proposals 2011-2018. Total number of funded projects in 2011-2018 is 91.

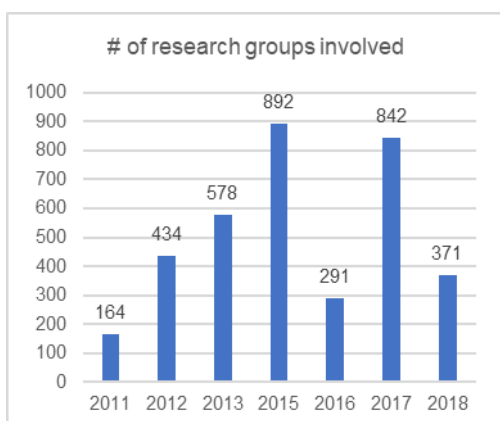


Figure: Number of research groups involved in JPND calls for proposals.

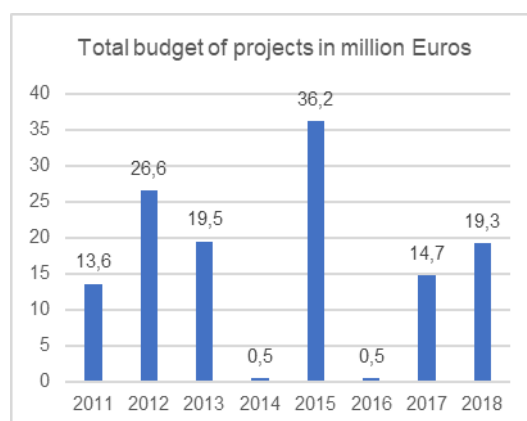


Figure: Total budget of JPND funded projects per call in million Euros. The total amount of allocated budget is 131 million Euros.

Multi-annual commitment of JPND Member States

- 25 Member States contributed to at least one of the joint transnational call for proposals. Comparing the 2 CSA periods, during the 2015-2019 JPsustainND / JPco-fuND-1 period the total amount of earmarked funding (not the actual project funding) increased by 13% for the 3 JPND regular JTCs for research projects and one rapid action call on working groups.
- The total JPND research portfolio was calculated at 2,217 million euros (566 million euros/year) in the 2017 JPND mapping exercise report, which represents a 53% increase on overall annual investment reported in 2011 (370 million euros/year).
- Notably since 2011, an approximate two-fold increase in annual spending on clinical and health & social care research as a proportion of total funding was reported, with a small decrease in basic research spend.

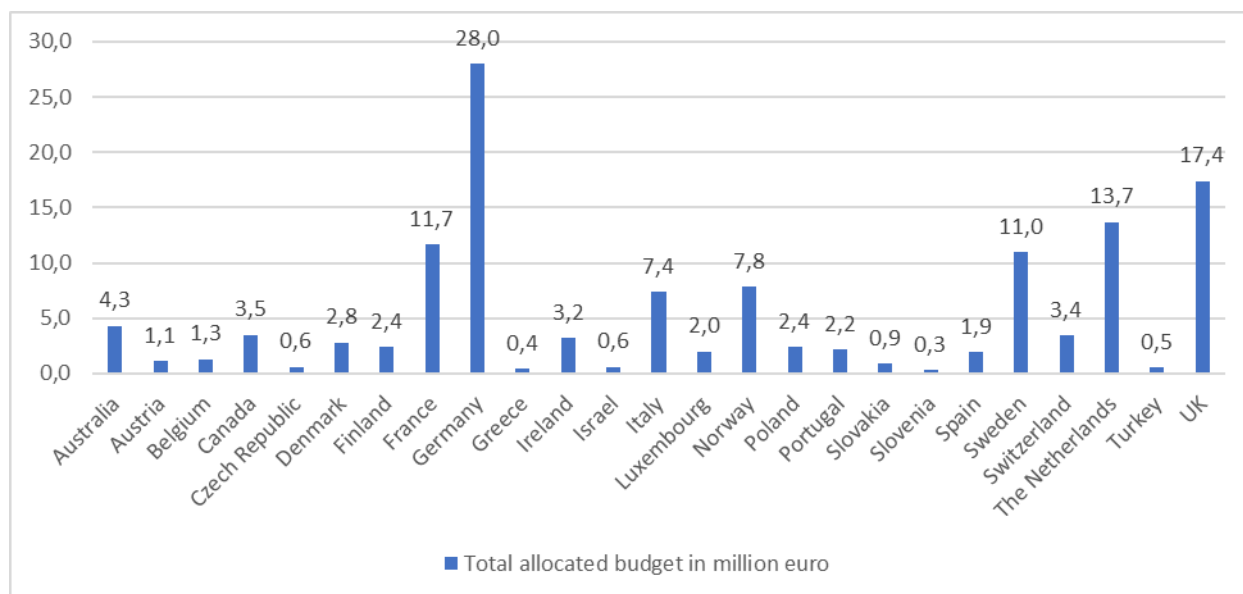


Figure. Funding allocations in JPND calls across JPND Member States. The total amount of allocated budget in JPND calls across various JPND Member States was 131 million euros.

Dedicated structure for long-term sustainability

- To increase the development and extension of JPND’s capacities, JP sustainND aims to create a dedicated structure responsible for long-term JPND management and implementation. The number of countries involved in JPND has more than tripled since the start of the programme.
- JPND has been exploring different possibilities for a sustainable long-term legalised management structure. Since the start of 2010, JPND has had an efficient management structure which is supported by the MB members.

Project results

- The total of 91 supported projects in the 10 JPND calls (20 working groups and 71 research projects) shows an uneven distribution across the 5 JPND scientific priorities with a major focus on the first 2 priorities (origin of ND and disease mechanisms and models).
- 15 projects from the JPND regular calls (2011-2013) and 20 from the rapid action calls (2014, 2016) have been finalised and have submitted a final report in the period 2016 - Q1_2019.
- 56 research projects from the regular JPND calls are still ongoing. No project was stopped prematurely.
- A total of 1013 publications in scientific journals with an impact factor varying between 1 and 31.6. were reported in 15 completed and 56 ongoing research projects. From the titles of these publications, it can be gathered that 50 are on prevention, 232 are on diagnosis and 123 are on treatment. 335 publications are on prediction / genetics, 143 on disease modelling, and 46 on care.
- JPND has delivered concrete high-quality research results in the area of ND, which are already taken up or can be taken up by the scientific research community, healthcare professionals and policy makers. In 17 JPND projects a total of 53 PhD, 41 post-doctorates and 29 other jobs were created and of these, 27 PhD and 22 post-doctorate positions were maintained.

Table. JPND / JPco-fuND research project output reported in annual and final reports

Publications and communications	Final reports N=15	Annual reports N=56	Total N=71
Peer-reviewed articles	522	491	1013
Books or book’s chapters	4	0	4
Reviews	27	0	27
Articles dedicated to general public	29	56	85
Dissertations	27	34	61
Others	44	59	103
Communications in scientific congresses	276	253	529
Total	929	876	1805

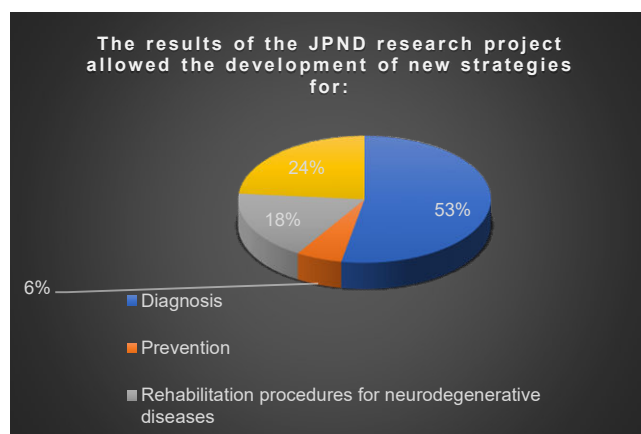


Figure. Potential health impact of JPND-supported projects reported by PIs in survey 2018 (N=17)

Non-project activities

- To align JPND to other activities across Europe, 8 Action Groups (AGs) were established as part of the first phase Implementation plan 2012-2014. These proceeded with their work in phase II (2015-2018) together with 3 more AGs.
- The 5 scientific priorities of JPND's Research Strategy are targeted by dedicated AGs. However, the different AGs have resulted in different initiatives like refreshing the SRIA, updating the research mapping, the development of a web portal for experimental models and a web portal for cohort studies, and organising an industry workshop.
- The different databases are accessible online on the JPND website and linked with the NIH's International Alzheimer's and Related Dementia Research Portfolio (IADRP).

Capacity building

- JPND has expanded its membership to 30 countries to promote global connections for ND research. A major effort was made to identify ongoing collaborations between JPND countries and other countries (Europe and beyond), with a view to the future participation of new countries in the formulation and implementation of JPND strategy.
- Countries like Czech Republic, Hungary, Slovakia, Slovenia, Romania participate in calls, but their share in funded projects is very limited.
- In the evaluation period, 2 countries, Australia and Bulgaria, have joined JPND as active members. 11 countries, including 3 EU countries (Malta, Latvia, Estonia) and 8 non-EU countries (Brazil, China, Cuba, India, Japan, Singapore, South Korea, USA) have shown interest in JPND. Two of these countries are already involved in JPND activities; Latvia participated in the call 2019 on Precision Medicine and conversations with USA have resulted in 5 projects twinning as a result of the 2017 call. Estonia and India have indicated that they would be willing to participate in future JPND calls.
- There is a collaboration with the World Dementia Council (WDC) and World Health Organisation (WHO) to strengthen contacts with targeted countries and to help promote a global research strategy.

Alignment of national and JPND research strategies

- Several actions were identified and implemented to promote alignment of research and innovation activities so that common agendas in the field of ND can be developed across Europe. These actions are designed to build on and increase the impact of programmes and initiatives related to ND. These activities include the Sharing of Research Strategies (e.g. SRIA), Centralising and Sharing Data (e.g. Global cohort portal and sharing it with NIH/IADRP), Mapping the Research and Innovation Landscape (Research portal and connected with NIH/IADRP), and Sharing Infrastructures (e.g. imaging and biobanks and collaboration with ESFRI).
- 165 research infrastructures / resources were identified and included in the mapping exercise that are relevant to, or potentially useful for investigation of, one or more of the NDs included under the JPND initiative. Two types of infrastructures for alignment, imaging and biobanks, have been identified and engagement with ESFRI has led to encourage the use of ESFRI platforms in the ongoing JPco-fund-2 call that was launched in January 2019. Further assessment is needed and actions need to be continued in 2019.
- Regular interactions with relevant JPND stakeholders took place to align call topics, priority setting in JPND SRIA and possibilities for collaborations.

Communication

- JP sustainND has sought to fully make use of the JPND dissemination and communications resources and experience gained since 2009 with a view to establishing JPND as a reference for European and global knowledge and innovation platforms in the area of ND.
- In the period 2015-2018, JPND developed and further established a number of tools for outreach including printed materials (e.g. flyers, factsheets of supported projects) and online tools (website with different additional sections, twitter feed, press releases as well as group emails forwarded via the JPND stakeholder database) to facilitate knowledge transfer of CSA-relevant information and information on JPco-fund ERA-NET to stakeholders and citizens.
- 443,428 users of the JPND website have been identified so far. The translation of select pages of the website into 24 languages of the JPND Management Board gave a significant boost in traffic to the JPND website, which has increased to an average of 164,000 visitors per annum. Twitter followers increased from 1186 in January 2017 to 1891 in February 2019. The JPND activity on this platform is good compared to other JPIs in the health area.
- Several JPND presentations were given at different events to engage with relevant stakeholders. The JPND research projects were also presented in many research conferences relevant to ND.

Executive Summary JPND External evaluation

The purpose of the external evaluation was to provide an independent review of JPND's performance to date, taking into account whether the programme has been conducted according to the JP sustainND Grant Agreement, and to provide recommendations for improvement.

The External Evaluation Committee's consensus is that JPND has been a very successful programme so far, not least with regard to co-operation and management. It has, amongst others: established the largest global research initiative in neurodegenerative diseases (ND), mobilised over €130m to fund transnational research projects, developed a number of international infrastructures to progress understanding of ND including the identification of common factors in different ND origin and progression, and engaged with a broad range of stakeholders, leading to the translation of some project results into societal benefit.

The review process, however, identified a number of areas of improvements challenges for JPND:

1. Funding and commitment
2. Number of countries
3. Collaboration with industry as well as health and patient organisations
4. Processes for scientific assessment, monitoring and evaluation
5. Making results from JPND known to science and society

The External Evaluation Committee considers the research results obtained so far to be promising and believes that it is possible to turn these challenges into opportunities, to achieve further societal and scientific impact. The organisational framework in which JPND decides to operate under will impact the achievement of these opportunities. The External Evaluation Committee recommends that the Management Board of JPND considers alternative structures for JPND going forward and how its membership should be organised. Three 'Strategic Options' have been considered:

1. Incremental development within the existing organisational framework, which would allow some of these issues to be addressed but leaves JPND dependent on EU funding for management activities.
2. Tiered membership structure, which would enable different countries to participate according to their means and strategic interests. This also implies that there would be a core group of the most committed countries that would lead the research strategy but with others having access to the results. This would be relatively easy to implement and could improve the visibility of JPND and its ability to form partnerships with other organisations and initiatives. However, it runs the risk of marginalising some members.
3. Legal entity for JPND, which would allow it to bid for other sources of funding as well as entering agreements with other organisations and initiatives. This should thus lower the level of dependency and the administrative burden for those members with limited resources. However, it is more complicated to establish and also runs the risk of marginalising some existing members.

The External Evaluation Committee's analysis of the three strategic options, in terms of their effectiveness in addressing the key challenges, has led to the recommendation that a process be started to investigate the possibilities for a tiered membership, which could lead to the establishment of a legal entity later. The Committee is aware that the Management and Scientific Advisory Boards of JPND have insights that will allow them to make more detailed preparations on how best to overcome the identified challenges and also to judge when the time is right for reorganisation. It is therefore proposed that the following actions should be started:

1. Establish a clear **vision** for what JPND wants to achieve in the next 10 years.
2. Agree on the **scope** of JPND going forward, i.e. should JPND continue to be global or focus more on strengthening European membership.
3. Determine the most **sustainable structure** for JPND, i.e. a means to organise JPND that in the long term allows control and direction of its activities.