

JUMPAHEAD

Grant agreement No.260774

Final summary report

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Executive summary

The JUMPAHEAD project was an FP7 coordination action that supported the implementation of JPND - the EU Joint Programme - Neurodegenerative Disease Research. It was a four-year project which began in 2010, funded by a two million euro FP7 grant (GA no. 260774). JPND aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases.

JPND was established as the pilot for “joint programming” – an unprecedented type of collaborative approach to research and a coordinating Management Board between the 23 JPND member countries was established in 2010. Since then, five additional countries have joined the initiative including Canada, bringing the total number to 28 countries, and making JPND the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases.

JUMPAHEAD built the foundations for the JPND initiative by supporting the development and implementation of the JPND Strategic Research Agenda, launched on February 7th, 2012, as well as its dissemination and evaluation.

The outputs of JUMPAHEAD over its 48 month duration included innovative ways of pooling national expertise and resources and the establishment of closer and robust research collaborations among the participating states in the field of neurodegeneration research. More particularly, JUMPAHEAD facilitated:

- The commitment of up to 100 million euro of funding in the period of 2012-2015, which is in addition to funds already being spent by national funding organizations;
- The launch of a pan-European Research Strategy (SRA) to guide neurodegenerative disease research activity in Europe over the next ten years;
- Formation of an international Scientific Advisory Board composed of eighteen top-ranking scientists from academic research, industry and patient organisations from across the EU and beyond;
- Generation of common procedures for joint transnational calls for research proposals;
- Creation of a research mapping database available on the JPND website.

The implementation of the JPND Research Strategy has already begun with a phased approach of annual activities and action groups over the period of 2012-2014, under the direction of the JPND Management Board.

JUMPAHEAD contributed to the European Research Area by addressing the existing fragmentation of national research programmes, and improving co-ordination amongst research funders and research activities. By doing so, and through active communication and engagement with stakeholders and the wider public, it ensures the maximum benefit for all European citizens from our research efforts into neurodegenerative diseases.

Summary description of project context and objectives

Neurodegenerative diseases such as Alzheimer's and Parkinson's are debilitating and largely untreatable conditions that are strongly linked with age. Amongst these disorders, the dementias are responsible for the greatest burden of disease, with Alzheimer's disease and related disorders affecting over 7 million people in Europe, and this figure is expected to double every 20 years as the population ages. It currently costs approximately €130 billion per annum to care for people with dementia across Europe, highlighting age-related neurodegenerative disease as one of the leading medical and societal challenges faced by EU society.

The objective of the Coordination Action JUMPAHEAD was to support the implementation of the pilot Joint Programming Initiative on combating neurodegenerative diseases, in particular Alzheimer's disease (JPND).

Although our understanding of the mechanisms of neurodegenerative disease has greatly improved over the past few years, there is no effective treatment able to stop or even slow down the deterioration of brain functions associated with these disorders.

To tackle this, pan-European health and societal challenge more effectively, 23 EU countries have launched the JPND - in October 2014, 28 countries were part of JPND. This is an innovative programme based on a common vision to improve the impact of their combined research effort to accelerate progress towards new treatments, identify preventative strategies, and improve patient care. The JPND is the first of the European Joint Programming initiatives which are designed to address the 'grand challenges' facing EU society in the coming years. These challenges are considered beyond the scope and resources of any one country to tackle.

JPND is the largest global research initiative aimed at tackling the challenge of neurodegenerative diseases. JPND aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with neurodegenerative diseases.

The ultimate goal of JPND is to find cures for neurodegenerative diseases and to enable early diagnosis for early targeted treatments. However, it is not possible to give definitive predictions on how long this might take to happen.

In the interim, JPND has identified through its Research Strategy common research goals that would benefit from joint action between countries in order to accelerate progress on solutions that can alleviate the symptoms, and lessen the social and economic impact for patients, families and health care systems.

There were three main components to this work:

- Improve the scientific understanding of the disease.
- Improve the medical tools available to doctors to identify and treat the disease.
- Improve the social care and structures available to assist patients, their families, and health service providers so that patients can receive optimum care at all stages of their illness.

JUMPAHEAD built the foundations for this initiative by supporting the development and implementation of a Strategic Research Agenda, as well as its dissemination and evaluation. This was achieved under the direction of the JPND Management Board.

The JUMPAHEAD coordination action, through the Work package 1 (WP1), provided the necessary administrative and logistical support to the meetings of the Management Board and the Scientific Advisory Board required for the development and implementation of the strategic research agenda. The development and implementation of this agenda is undertaken by the WP2 and WP3.

The five work packages of JUMPAHEAD were the following:

Number	Name	Lead organisation
Work package 1	Management & coordination	Inserm
Work package 2	Development of the Strategic Research Agenda	MRC
Work package 3	Implementation of the Strategic Research Agenda	BMBF
Work package 4	Communications and dissemination	HRB
Work package 5	Framework for monitoring and evaluation of JPND	ZonMw

The main objectives of JUMPAHEAD were therefore:

- the mapping of National and European research programmes (through WP2)
- the definition of strategic and scientific priorities that would benefit from coordination at the European level (through WP2)
- the definition of framework conditions to implement the SRA, i.e. political, legal, regulatory and financial arrangements (through WP3)
- the implementation of joint and coordinated research activities responsive to stakeholder interests (through WP3)
- the engagement of stakeholders through a communication plan to ensure the ultimate translation of research outputs into practice and policy (through WP4)
- the evaluation and monitoring of the joint activities (through WP5).

Description of the main S&T results/foregrounds

WP1- Management and coordination

Objectives

The overall objective of this work package was to ensure an efficient and professional management of the JUMPAHEAD coordination action and the JPND initiative in order to continuously orientate all activities towards the objectives and to ensure their fulfilment within time plan and budget.

Governance

The management structure of the JPND initiative is comprised of:

- Management Board (MB)
- Executive Board (EB)
- Scientific Advisory Board (SAB)
- Secretariat (Inserm Transfert, France)

The Management Board is the decision making body. It seeks advice from the Scientific Advisory Board on the Strategic Research Agenda and related matters.

The Executive Board supports the Management Board in all aspects concerning the preparation and implementation of decisions.

The Secretariat organises the day to day management and implements those tasks assigned to it by the Management Board and the Executive Board. It takes the necessary actions and reports accordingly to the MB and the EB.

The JPND Management bodies exert their mandate with the utmost regard to transparency and fairness. Decisions will be governed by equal treatment and taking ethically relevant aspects in due account. In order to tackle major societal challenges, reasonable continuity of the management structure shall be ensured.

The JPND Management Board has appointed a Scientific Advisory Board (SAB) composed of the most pre-eminent scientists in the field of neurodegenerative diseases, with expertise across basic, clinical and healthcare/social research areas covered by JPND. The SAB is led by Thomas Gasser (Chair) and Martin Rossor (Vice-Chair). In August 2013, the membership of the SAB was expanded to include scientific representatives from industry and patient organisations. The SAB currently comprises 18 members.

JPND conducts a series of regular informal interviews with SAB members about the latest in neurodegenerative disease research. These can be found on the News & Media page of the JPND website.

Participants

The five workpackages in the project were carried out by 13 different organizations:

	Name	Short name	Country
1	Institut National de la Sante et de La Recherche Medicale	Inserm	France
2	Medical Research Council	MRC	United Kingdom

	Name	Short name	Country
3	Federal Ministry of Education and Research	BMBF	Germany
4	Deutsches Zentrum fuer Luft – und Raumfahrt	EVPT-DLR	Germany
5	Health Research Board	HRB	Ireland
6	The Netherlands Organisation for Health Research and Development	ZonMw	Netherlands
7	Ministero Dell'Istruzione, Dell'Universita'E Della Ricerca	MIUR	Italy
8	The Scientific and Research Council of Turkey	TUBITAK	Turkey
9	Instituto De Salud Carlos III	ISCI	Spain
10	Institute of Neuroimmunology – Slovak Academy of Sciences	NUI-SAV	Slovakia
11	National Office for Research and Technology	NKTH	Hungary
12	Inserm-Transfert SA	IT	France
13	Swedish Research Council	V-SRC	Sweden

WP2- Development of Strategic Research Agenda

WP2 has successfully delivered its objectives as set out in the JUMPAHEAD grant, namely to:

- Undertake a mapping exercise to ascertain the current EU-wide asset map for neurodegeneration research, as well as provide an information resource for the research community.
- Develop research priorities for future JPND activity, based upon expert and stakeholder perspectives.
- Deliver a holistic research strategy to guide JPND delivery over the next decade.

These are further detailed below:

Mapping exercise of National and European programmes

The first goal of JPND was to establish a joint Strategic Research Agenda (SRA) to guide research activity and investment over the coming decade.

To underpin development of the JPND SRA and ensure that the recommendations made paid due consideration to the existing research landscape, an exercise to map national and European research and infrastructure relevant to neurodegenerative diseases (ND) was conducted.

The primary aim of this exercise was to give an objective view of the scale and scope of research activity in ND amongst JPND member countries. This information was used to identify gaps and opportunities JPND could build upon and clarify medium to long-term research needs, objectives and priorities. The data collected also provides a baseline for monitoring spend on ND research activity and resources relevant to ND across Europe.

The parameters and specifications for the mapping exercise were designed in conjunction with the JPND Scientific Advisory Board to ensure that the data captured would be useful to both JPND and researchers working in the field. The parameters and specifications of what was included in the survey can be found by clicking [here](#).

2011 mapping exercise

A report summarising and analysing the data captured during the 2011 mapping exercise can be found here: <http://www.neurodegenerationresearch.eu/initiatives/mapping-exercise/2011-report/>

A brief summary of the information can also be found in Annex 2 of the JPND Research Strategy:
<http://www.neurodegenerationresearch.eu/initiatives/strategic-research-agenda/>

It is proposed that for comparative purposes a repeat mapping exercise for research programmes or grants will be conducted in 2014.

Searchable database

The secondary aim of the mapping exercise was to provide an updateable, publically accessible, database as a resource for the scientific community and other interested parties. The resource is available through the JPND website at:

<http://www.neurodegenerationresearch.eu/search-our-database/>

Scientific priorities of the SRA by SAB

Research priorities addressing the required areas and considerations were identified across the whole spectrum of research activity with the help of the JPND SAB, additional academic experts and other stakeholder groups.

Prioritisation was achieved through three domain specific academic workshops, involving 100 scientific opinion leaders, plus stakeholder workshops with industry and patient and carer groups. An ‘integrating’ workshop was held at the end of this process bringing together 45 academic experts and key stakeholders in order to assemble a balanced list of future priorities.

Additional one-to-one consultations were sought with underrepresented sectors (eg. certain commercial areas and health professionals), while a public consultation on the outputs of the integrating workshop was also undertaken.

Further details and reports summarising all workshops and consultations can be found on the JPND website:

<http://www.neurodegenerationresearch.eu/initiatives/strategic-research-agenda/delivery-of-the-sra/>

Strategic prioritisation and delivery of the SRA

One of the first steps towards realising the aims of JPND was the creation of a Strategic Research Agenda (SRA) to provide a framework for future investment and address how the European research effort can most effectively be harnessed to improve prevention, diagnosis, treatment and patient care for neurodegenerative diseases.

The final version of the SRA can be found on the JPND website:

www.neurodegenerationresearch.eu/initiatives/strategic-research-agenda

The JPND Research Strategy, which forms the basis of the SRA, was launched on February 7th, 2012.

www.neurodegenerationresearch.eu/initiatives/strategic-research-agenda/sra-launch

Five Thematic Priorities for future research have been identified:

- The origins of neurodegenerative disease
- Disease mechanisms and models
- Disease definitions and diagnosis
- Developing therapies, preventive strategies and interventions
- Healthcare and social care

JPND is now implementing its strategy and a first-phase implementation plan has been agreed for 2012-2014.

WP3- Implementation of Strategic Research Agenda

Further to the publication of the SRA a first-phase JPND Implementation Plan has been agreed for the period of 2012-2014. The plan has three major action areas:

- Action Groups to determine research needs and opportunities
- Action Groups to promote engagement, commitment and partnerships
- Annual Calls for Proposals

Seven suggestions for new Joint Transnational Calls (JTCs) were formulated in the implementation plan including the ones developed under the aligned CoEN programme¹. In addition, task forces were suggested for topics that still required further work and whose output would lead to further concrete activities for immediate implementation at a later point.

Suggested JTCs should address each of the following priority areas:

- Genetic, epigenetic & environmental risk factors
- Cell and animal models for the identification of mechanisms underlying ND
- Cross-disease analysis of pathways
- Preventive strategies
- Evaluating healthcare policy strategies and interventions
- Systematic Review(s) of 'pathways to care'
- Palliative and end-of-life care

Over the period of 2012-2014, JPND launched calls for proposals each year to address these high priority areas. The list of JTCs is available in this report.

Also as part of the multiple JPND Alignment Actions, four expert-led Action Groups are determining transnational research needs and opportunities in the following priority areas:

- Longitudinal Cohort Studies (with workstreams addressing both disease-based and population-based cohorts)
- Animal and Cell Models
- Assisted Living Technologies
- Palliative Care

Each Action Group aims to recommend the most appropriate approach to be adopted by JPND for implementation of each of these research priorities.

In addition the JPND Executive Board is leading specific actions to promote engagement, commitment and partnership towards the implementation of specific priorities. These actions include:

- Engagement and Partnership with Industry
- Engagement and Partnership with the European Commission and other international initiatives
- Linking and alignment of national plans and initiatives
- User and Public Involvement in neurodegenerative disease research

¹ CoEN is based on a joint programme initially agreed between the Canadian Institutes of Health Research (CIHR), the Deutsche Zentrum für Neurodegenerative Erkrankungen (DZNE, Germany) and the Medical Research Council (MRC, United Kingdom). The initiative was subsequently joined by the Flanders Institute of Biotechnology (VIB Flanders, Belgium), the Health Research Board (HRB), Ireland / Science Foundation Ireland (SFI), and the Ministero della Salute (MDS, Italy).

<http://www.neurodegenerationresearch.eu/initiatives/network-of-centres-of-excellence/>

Each year, JPND considers the remaining priorities of the Implementation Plan and launches activities based on the identified needs arising from the work of the Action Groups in addition to the research areas either oversubscribed or unaddressed in the previous year's Calls for proposals.

JPND action groups

Assisted Living Technologies

Assisted living technologies such as ICT/smart technology offer enormous potential in the development of effective measures for prevention, intervention and care for people with neurodegenerative diseases/dementia and their (in)formal carers.

To join forces and align priorities in this area, JPND and the Article-185 initiative -Ambient Assisted Living Joint Programme (AAL JP), are working together towards developing recommendations for joint actions in the area of assisted living technologies for neurodegenerative diseases.

A JPND Action Group, containing members of both initiatives, is working to identify where JPND and AAL JP priorities and activities can be aligned, or new activities identified, and is organising activities to bring together important stakeholders in this area including users, academia, small businesses and the ICT and service industry.

- *2014 Joint Workshop, Amsterdam, The Netherlands*

The Action Group jointly organised an expert workshop in the Royal Tropical Institute, Amsterdam, Netherlands on Jan. 27th, 2014.

The main objectives of the workshop were to identify gaps and potential benefits for collaboration and to recommend future joint actions and opportunities.

A copy of the workshop report is available on the JPND website.

- *Neurodegenerative Disease an area of focus for AAL JP*

In the AAL Joint Programme, stimulating the development of ICT-based solutions to support independence of older adults is a priority.

Indeed, approximately 25% of current AALJP projects are developing solutions for support and care of older adults with cognitive impairments/dementia and their (informal) carers.

- *2013 AAL Forum, Norrköping, Sweden*

The Action Group jointly-organised a session at the 2013 AAL Forum in Norrköping, Sweden, on Sept. 25th, 2013. The Forum is the annual platform for the ever-increasing European AAL community to meet and discuss topics relevant for improving the AAL JP as well as the adoption of AAL solutions in the market.

Industry Partnership

Following the substantive participation of relevant industry groups in the development of the JPND Research Strategy, JPND is seeking to develop public-private partnerships with industry in key priority areas for implementation.

JPND is already engaging with the Innovative Medicines Initiative to align scientific priorities with the pharmaceutical industry and to promote public-private partnerships.

JPND will look to expand this engagement to the Diagnostic, IT, Medical Device and Imaging industries, as well as Small-to-Medium Enterprises with relevance to neurodegenerative diseases.

Animal and Cell Models

It is widely acknowledged that the use of improved animal and cellular models of neurodegeneration will lead to a more complete understanding of the biological basis of disease mechanisms and evolution.

In general, existing models do not reproduce all aspects of the human diseases, yet they have provided a significant support to the definition of many disease-associated mechanisms.

A JPND Action Group on Animal and Cellular Models in Neurodegeneration Research met during 2013 and has reported back to JPND. The group was tasked with:

- documenting the experimental models currently utilized for the study of specific neurodegenerative diseases and new therapies
- identifying the shortcomings of the models currently available
- identifying the need for novel models and lines of intervention

The report provides a broad panorama of the models currently available and a critical overview of their limitations, thereby suggesting lines of intervention within the reach of the JPND community that may include:

- funding of competitive calls
- organization of initiatives aimed at harmonizing research activities in this field
- providing assistance to the scientific community to improve current experimental models

Priorities for action will be set by JPND Management Board for announcement in 2014.

The report is available on the JPND website.

Palliative and End-of-life Care Research

It is also widely acknowledged that a severe lack of knowledge exists for the area of palliative and end-of-life care, in particular for care of persons with neurodegenerative diseases such as dementia.

Participants at the JPND Palliative Care research workshop in Amsterdam on June 25th, 2014

The JPND Research Strategy recommends that further research should be undertaken to inform palliative and end-of-life care, which should appropriately integrate research into the complex ethical issues relating to neurodegenerative diseases.

A JPND Action Group on Palliative and End-of- Life Care is developing recommendations for JPND-supported actions in this area.

The Action Group is identifying ongoing regional, national and international initiatives with a relevant research focus on palliative/end-of life care, with the objective of bringing relevant groups together to identify where JPND can make an impact.

Expert-led Workshop, Amsterdam, June 25th, 2014

The JPND Action Group on Palliative Care organised an expert-led workshop in Amsterdam airport on June 25th, 2014 to identify capacity-building and integrative research opportunities in this area, and to recommend future JPND actions and activities. Workshop agenda and presentations are available on the JPND website.



Patient and Public Involvement (PPI)

Most health and healthcare research would be impossible without the active involvement of patients. The last 20 years has seen a growing interest at a European, national and local level in patient engagement and in particular a focused interest in patient and public involvement (PPI) in research.

Several of the themes and 'enabling activities' of the JPND Strategic Research Agenda refer to principles and activities of PPI for example; 'Connection to Policy Makers', 'Communication and Outreach' and 'Stakeholder Engagement'.

JPND Management Board members have since determined that PPI should be an integrated part of SRA implementation, and a JPND Action Group was established in June 2012 as part of a number of actions to promote engagement, commitment and partnerships.

The remit for the Action Group is “to promote Public Involvement in Research in order to improve the way that neurodegenerative disease research is Prioritized, Commissioned, Undertaken, Communicated and Used”.

A draft plan for implementation of PPI in JPND Research was presented to the Management Board in October 2013.

The Action Group was expanded in 2014 to form a JPND PPI Stakeholder Advisory Board, with the addition of senior leaders of relevant parts of the international scientific, clinical, healthcare and social care systems. The primary aim of the Board will be to provide rapid and frank feedback and early advice from the broad PPI stakeholder community to JPND in relation to implementation of PPI in ND research.

Alignment of National Activities

A JPND Action Group is seeking to identify areas within JPND countries whereby nationally-funded investments and activities can be aligned in order to increase impact on the challenge of neurodegenerative diseases (ND). Both ND-directed investment under national programmes and exploitation of national infrastructures to support ND research are being explored.

The remit of this Action Group is to:

- Progress priorities identified in the JPND Research Strategy through increased coordination of national activities.
- Identify existing national resources and initiatives where potential exists for linking, harmonization and sharing of knowledge to address research questions specific to neurodegenerative diseases.
- Identify approaches that may facilitate wider access to national technology platforms or infrastructures such as biobanking, neuroimaging or informatics capabilities, and promote the sharing of data and resources.

Engagement and partnership with non-EU countries

The main objective of this Action Group is to present and disseminate JPND outside Europe. Canada has already been accepted as a third country, and will become a full member in May 2014. A protocol to include third countries has been accepted by all JPND member countries. Discussions are currently open with the USA and other G8 countries. Moreover, JPND has been considered as a stakeholder of the recent G8 Health summit that was held in London in December 2013, under the UK Presidency. JPND and JPND members are participating in the ongoing G7 Legacy Events and associated mapping and action groups, under the auspices of the OECD.

Annual Calls for Proposals

JPND is implementing the priorities identified in its research strategy through a range of large-scale programmatic initiatives.

During the first phase of implementation (2012-2014), JPND launched Joint Transnational Calls in Quarter 4 (Oct-Dec) each year to address high priority areas in neurodegenerative disease research².

² The JPND diseases are:

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), Spinal muscular atrophy (SMA)

A pre-call announcement, with indicative call topics is anticipated in early Quarter 4 (October) each year.

This section contains information on Calls for proposals that were launched under the JPND Annual Calls for proposals aimed at supporting transnational collaborations in the field of neurodegenerative disease research. A summary of the different calls is provided below:

- **2014:**
 - “A Call for Proposals for Working Groups to Inform Cohort Studies in Neurodegenerative Disease Research”
- **2013:**
 - “A call for European research projects for cross-disease analysis of pathways related to neurodegenerative diseases”
 - “A call for European research projects for pilot studies for preventive strategies related to neurodegenerative diseases”
- **2012:**
 - “A call for European research projects for the identification of genetic, epigenetic and environmental risk and protective factors”
 - “A call for European research projects for the evaluation of health care policies, strategies and interventions”
- **2011:**
 - “Pilot JPND Joint Transnational Call for optimisation of biomarkers and harmonisation of their use”

Also two calls were launched by the Centres of Excellence in Neurodegeneration (CoEN) programme.

Details of individual projects can be found on the JPND website. More details about each call can be found below.

Optimisation of biomarkers (2011)

It is widely perceived that the availability of sensitive and specific biomarkers for the diagnosis and the monitoring of progression of neurodegenerative disorders, sufficiently robust to be used in large multicentric trials, is one of the greatest unmet needs in the field of neurodegenerative disease research.

Therefore, an immediate issue to be addressed is the development of optimally informative biomarkers to provide a solid basis for the establishment of risk-stratified patient cohorts and for upcoming multicentric diagnostic and therapeutic trials and to ensure stakeholder agreement regarding their use.

On 13 May 2011 a JPND joint transnational call was launched between 21 countries, to encourage novel approaches to the development of optimally informative biomarkers and harmonisation of their use. Applications were invited from collaborative consortia of researchers from participating countries.

The total fund for this call was over 16 million euro (for all participating countries).

Four projects are currently being funded under this call and started in 2012.

European research projects for the identification of genetic, epigenetic and environmental risk and protective factors for Neurodegenerative Diseases (2012)

It is widely perceived that a lack of knowledge regarding the causes of specific neurodegenerative diseases is one of the greatest unmet needs to be addressed in ND research. Therefore, it is of utmost importance to better understand:

- the genetic, epigenetic and environmental factors that underlie an individual's risk and resilience
- the triggering events leading to illness
- the relationship and interplay between these factors and their relative importance
- the role of potential environmental and behavioural modulators.

Such knowledge will advance the identification of new targets to which second generation pharmacological therapies can be directed and will ultimately help to advance preventive strategies. On December 10th 2012 a JPND joint transnational call was launched between 19 countries, to establish a limited number of ambitious, innovative, multi-national and multi-disciplinary collaborative research projects that will add value to existing research by identifying new genetic, epigenetic and environmental risk and protective factors associated with neurodegenerative disorders. Applications were invited from collaborative consortia of researchers from participating countries. The call was conducted simultaneously by the participating funding organisations in their respective countries and coordinated centrally, with a single proposal submission and peer review system. The proposal submission deadline was the 19th of March, 2013.

The total fund for this call was over 19 million euro (for all participating countries).

Five projects are currently being funded under this call.

European research projects for the evaluation of health care policies, strategies and interventions for Neurodegenerative Diseases (2012)

On December 10th 2012 a JPND joint transnational call was launched between 14 countries, to support appropriate approaches to understanding health care policies, strategies and interventions. The aim of the call is to assess and compare pathways to care, through evaluating access to, the quality and the cost effectiveness of care provision and support for patients with neurodegenerative diseases across different care settings.

Research will be supported which addresses the levels of both health / social care delivery at the macro level (system and infrastructures) and at the individual level of persons with ND and their carers. Proposals may include research based evaluation of interventions relevant for those with ND. Where appropriate, proposals should include validation and improvement of outcome measures that are relevant for persons with ND and their carers in order to provide reliable tools for measurements of health related quality of life (HRQoL).

Applications were invited from collaborative consortia of researchers from participating countries. The call was conducted simultaneously by the participating funding organisations in their respective countries and coordinated centrally, with a single proposal submission and peer review system. The proposal submission deadline was the 21st of March, 2013.

The total fund for this call was over 10 million euro (for all participating countries).

Six projects are currently being funded under this call.

A call for European research projects for pilot studies on preventive strategies related to Neurodegenerative Diseases (2013)

Recent results from epidemiological studies in aging suggest that preventive strategies may modify both the risk of developing neurodegenerative diseases and of symptom progression. However, it is not yet known whether these findings can be translated into efficacious preventive strategies that specifically target healthy persons, at risk populations or early stage patients with neurodegenerative diseases. Therefore, more research is needed to develop proof-of-concept for the design of prevention trials aimed to investigate the effect of complex interventions.

On December 2nd 2013 JPND launched a joint transnational call between 16 countries in order to encourage interdisciplinary “pilot” studies for the design of preventive strategies related to neurodegenerative diseases.

Proposals should entail multidisciplinary studies which may focus on new paradigms for multimodal preventive interventions including culture specific aspects, on harmonisation initiatives, or on proof-of-concept, and feasibility studies. Proposals may include research-based evaluation of interventions and validation of outcome measures.

The total fund made available for this call is over 11 million euro (from all participating countries). Under this call, each country funds its own national participants in successful collaborative proposals, according to their national budget allocation.

Five projects are currently being supported under this call.

A call for European research projects for cross-disease analysis of pathways related to neurodegenerative diseases (2013)

There is clinical, genetic and biochemical evidence that similar molecular pathways are relevant in different neurodegenerative and other chronic diseases. Therefore, clinical phenotypes alone seem insufficient to provide an understanding of the underlying mechanisms involved, and to be the sole basis for prognosis and diagnosis of neurodegenerative diseases. On December 2nd 2013 JPND launched a joint transnational call between 16 countries, for multidisciplinary proposals to perform network analyses in different neurodegenerative and other chronic diseases to elucidate the underlying mechanisms involved. The combined analysis of diseases across traditional clinical boundaries may lead to a re-definition of clinical phenotypes and new approaches in the treatment of neurodegenerative diseases.

The aim of the call was to establish a limited number of ambitious, innovative, multi-national and multi-disciplinary collaborative research projects that:

- combine experimental approaches from fundamental, pre-clinical and/or clinical with computational approaches
- perform network analyses in different neurodegenerative and other chronic diseases to elucidate the underlying mechanisms common and differing in the investigated diseases
- will add value to existing research by analysing diseases across traditional clinical boundaries, thereby gaining deeper understanding of the patho-physiological mechanisms of the diseases.

The total fund made available for this call is over 12 million euro (from all participating countries). Under this call, each country funds its own national participants in successful collaborative proposals, according to their national budget allocation.

Ten projects are currently being supported under this call.

Longitudinal Cohorts (2014)

Longitudinal-based cohort studies are tremendously important resources for multi-disciplinary research, in particular for research into the causes of diseases (e.g. determining risk factors). It is also widely acknowledged that collaboration across JPND member countries would add great value to current efforts and is urgently required for research into neurodegenerative diseases.

JPND is currently investigating potential actions for both disease-based and population-based longitudinal cohort studies, whereby current member state-based or EC-supported activities can be expanded or better exploited, or new activities identified.

A specific Action Group has been tasked with producing a report that:

- Takes stock of current longitudinal cohort studies for both ND-based and general population-based studies of relevance

- Determines how JPND adds value to existing cohort investments
- Identifies gaps and any case for new activity in areas of unmet need
- Scopes the emerging scientific opportunities
- Makes recommendations to the JPND Management Board

The report spans general population-based, targeted (preclinical) and disease-focused cohorts.

Valuable information that is immediately accessible includes:

- analyses of longitudinal and disease cohort studies
- an analysis of imaging studies
- a cohort reference list with web links

Implementation of JPND actions in this area will be based on the advice in the report. The options for implementation are based on an analysis of the opportunities presented by current European longitudinal cohort capability as well as comparison with selected international studies. Recommendations span coordination, funding and policy areas. Priorities for action will be set by JPND Management Board for announcement in 2014.

On April 23rd, 2014, JPND launched a rapid action call for leading scientists in the field to establish working groups to enhance the use of existing longitudinal cohort studies for neurodegenerative disease (ND) research. The call closed on June 16th, 2014 and ten international working groups are currently being supported under the call. The report and more details about the proposals funded can be found on the JPND website.

Overview of the different calls and call statistics:

Year	No of participating countries	Budget	No of proposals received	Research topic	No. of Projects funded
2011 (pilot)	23	13.6 M €	14	European research projects for the optimization of biomarkers and harmonisation of their use between clinical centres	4 projects 82 research groups Started in 2012.
2012	21	16 M €	52	European research projects for the identification of genetic, epigenetic and environmental risk and protective factors for Neurodegenerative Diseases	5 projects 43 research groups Started in 2014
2012	13	9.0 M €	22	European research projects for the evaluation of health care policies, strategies and interventions for Neurodegenerative Diseases	6 projects 41 research groups Started in 2014
2013	16	13 M €* [†]	92	European research projects for Cross-disease analysis of pathways related to	10 projects 50 research groups

Year	No of participating countries	Budget	No of proposals received	Research topic	No. of Projects funded
				Neurodegenerative Diseases	Start in 2015
2013	16	11.7 M €*	35	European research projects for Pilot Studies on Preventive Strategies related to Neurodegenerative Diseases	5 projects 20 research groups Start in 2015
2014	10	0.5 M €	22	Working Groups to Inform Cohort Studies in Neurodegenerative Disease Research	10 projects Start in 2014

* earmarked

In addition, two COEN calls were launched in 2012 and 2013 to address Neurodegeneration research. 13 projects were awarded for a total of 8 M€. More information is available on the JPND website and the COEN website www.coen.org.

The next call is being planned in January 2015, with a commitment of 27 M€ from the participating countries.

WP4- Communication and Dissemination

Identification of appropriate Stakeholders

A JPND Stakeholder Database was created by the JPND Communications Executive. It is being populated with contact details from relevant stakeholder organisations from each country participating in the JPND initiative.

The database will ensure that relevant stakeholders remain informed concerning the outputs, results and initiatives of JPND. Pan-European organisations and JPND Management Board representatives are being approached to enter details of their individual members and country-specific contacts.

Stakeholder details will remain securely stored on the server of the Health Research Board, Ireland. Access to the database will be centrally coordinated through the JPND Communications Manager. No contact details will be shared with individuals outside of the JPND initiative.

The database now contains over 2300 contact details from all identified stakeholder groups in over 30 countries. Over 200 contact details have also been received via a JPND website sign-up process.

<http://www.neurodegenerationresearch.eu/contact/stakeholder-database-entry/>

Develop plan for engagement with stakeholders

JPND recognises stakeholder engagement as an on-going, iterative activity to last throughout the lifetime of JPND, beyond the (now extended) JUMPAHEAD action. A JPND Stakeholder Engagement Plan was approved by the Executive Board in May 2013.

This plan will continue to be revised according to the sustainability plan of JPND.

Execute plan for engagement with stakeholders

The plan is being executed on an ongoing basis. Significant results include:

- Development of a clear JPND policy position on international collaboration and participation

of Third Countries in JPND (available on the JPND website).

- Development and regular update of Dissemination and Communication Guidelines for both JPND-funded projects and JPND representatives/participants, designed to encourage dissemination and communication as part of JPND activities.
- Contributions to the work of several SRA implementation action groups: identification of stakeholders, preparation of background documents, organisation of meetings.
- Promotion of knowledge-sharing to encourage the development of national plans in the area of ND research (e.g. providing templates, mapping existing plans, liaising with MB members).
- Organisation and support of JPND participation at multiple major international events, targeting individual stakeholders groups.
- Regular liaison with media representatives on behalf of JPND, securing and editing copy for several ‘op-ed’ articles on JPND in leading international publications (e.g. The Lancet Neurology, Nature Magazine and International Innovation Magazine).
- Raising the profile of neurodegenerative diseases among policy makers and research funders at the national and international level.
- The JPND public website www.neurodegeneration.eu / www.jpnd.eu acts as the public face of JPND. New additions to the website include Research News and press-related material, as well as social media channels (Twitter, Youtube, Flickr, Slideshare).
- Creation and promotion of a pilot online partnering tool tailored to fit JPND stakeholder needs, as a support to applicants to the Annual JPND Calls for proposals. The tool is designed to enable potential applicants to JPND calls to find collaborators worldwide thus encouraging greater collaboration across existing ND disease boundaries and research communities.
- Regular liaison with media representatives on behalf of JPND, securing and editing copy for several ‘op-ed’ articles on JPND in leading international magazines (e.g. Research Europe Magazine, Pan-European Networks Magazine, NEUROPEXNEWS Blog, Dementia in Europe Magazine, International Innovation Magazine, The European Files Magazine).
- Supported engagement at the national level towards the development of a national strategy for neurodegenerative diseases.

WP5- Framework for monitoring and evaluation of JPND

In line with the JPND Research Strategy, JPND has established a monitoring and evaluation framework to develop indicators of success for JPND and to monitor the merits of the new Joint Programming approach to performing neurodegenerative disease research on the European level. The framework, fully integrated as an element of JPND, was created as a deliverable of the JUMPAHEAD action. It includes a set of performance indicators and a questionnaire for participating countries to investigate attitudes and opinions towards the JPND initiative.

The framework has relevance for other Joint Programming Initiatives (JPIs), in particular to those in other health domains, to understand the effects of the process of Joint Programming.

A link to the published framework report and an overview presentation of the report are available on the JPND website.

Definition of indicators of success

JPND has developed a logical framework for the analysis of the objectives, activities and intended outputs, outcomes and impacts of the Joint Programming Initiative on Neurodegenerative Diseases. The framework provided the basis for the indicators of success to be used in the monitoring and evaluation of the initiative.

The logical framework was based on the outline of JUMPAHEAD, the EC communications on JPND and the recently launched Research Strategy. In addition, interviews were conducted with key stakeholders to further refine the framework. Interviews were performed with the following members of JPND's Executive Board, Steering Committee and Scientific Advisory Board.

A report on monitoring and evaluation of JPND has been approved by the Management Board³. This document contains two aspects of the process of monitoring and evaluation of the EU Joint Programming – Neurodegenerative Diseases Research (JPND):

- The framework for monitoring and evaluation including a set of indicators of performance and;
- A questionnaire amongst participating countries to investigate the attitude and opinions towards the initiative.

This analysis has subsequently been used to operationalise the concepts into a set of indicators of performance that will be used in the monitoring and evaluation process.

The set of indicators included indicators that can be used for (bi-)annual monitoring exercises of JPND, and those that are specifically suited for its (mid-term and final) evaluation. They were categorised according to the information they provide to the process of monitoring and evaluation:

- **Input indicators** are used to describe the resources used for the implementation of JPND;
- **Output indicators** relate to goods, services, technology and knowledge directly produced due to JPND activities;
- **Outcome indicators** show the initial results of the intervention providing the reason for the programme and are less tangible than outputs;
- **Impact indicators** measure the long-term socio-economic changes JPND brings about.

For JPND in particular two types of indicators have been identified following JUMPAHEAD's workplan:

1. **Type A:** these monitor the effect of JPND on (European) research programming, research policy and funding (the concept of joint programming).
2. **Type B:** these monitor the scientific and societal impact of JPND research on degenerative diseases.

Detailed definitions of each indicator, their intended focus and the data sources that will be used to collect the information are included in the monitoring and evaluation report.

Measurement indicators of success

A report containing the results of the first monitoring cycle of JPND have been presented. The report contains the following elements: a brief overview of the main observations, the methodology used to derive the set of indicators of performance and the final set of indicators of performance (recapitalisation of the information from the monitoring and evaluation report). The report furthermore addressed both the input and output indicators, included their values approximately three years after the start of JPND. The information has been collected by making use of various data sources, as defined in the monitoring and evaluation framework, amongst others:

- The minutes of the Management Board Meetings;
- JPND's Research Strategy that has been published in February 2012;

³ The monitoring and evaluation framework and an overview presentation can be found on JPND's website: <http://www.neurodegenerationresearch.eu/initiatives/monitoring-and-evaluation/>

- Information about the annual calls for proposals that have been launched; and
- A questionnaire amongst participating countries to investigate attitudes and opinions towards the initiative.

Finally the report presented the results from the questionnaire amongst participating countries regarding the foreseen future of JPND.

Investigate Member States attitudes towards JPND

JPND developed a 19-item questionnaire that aims to measure the attitudes of member states to the JPND. The electronic questionnaire has been distributed amongst all members of JPND's Management Board.

The questionnaire focused on the expectations, motivations and foreseen effects of JPND both within the own organisation and within the national research-funding context. It also contained questions focusing on the current functioning of JPND. The questionnaire addressed issues such as possibilities to mobilise national funding for JPND and to align national programmes with programmes in other countries, feasibility of executing collaborative projects within the JPND framework and expected benefits of JPND relative to other EC programmes. The questionnaire was divided in four main blocks:

1. General information on the type of organisation and the involvement in JPND
2. Expectations regarding JPND
3. Opinions on current JPND activities
4. Views on the future

An overview of all questions that have been asked can be found in the monitoring and evaluation report.

Independent monitoring of the JPND

JPND formed an independent review panel with three people who reviewed the strategic direction and implementation strategy of JPND.

The committee consisted of high-level experts with a background and experience in research strategy funding, understanding of the European context (research landscape) and issues concerned with cross-border funding. In order to have an independent view, the committee members are not involved with JPND's governance and processes.

Basically, the committee focused on JPND's governance and processes of strategic policy programming (strategic direction) that have led to the development of the Research Strategy (SRA) and its implementation plan. The following key questions have been formulated as the starting point for the committee to reflect on:

- Is the strategic direction and implementation strategy of JPND appropriate to be successful in establishing a more coordinated and well-organised Neurodegenerative Diseases research agenda and domain?
- Is JPND organised appropriately to achieve these goals?
- What advice can be given to enhance JPND's performance in the future?

The process of the external review consisted of the following stages:

- A preparation phase during which the external reviewers received a limited number of key documents to read in advance:
- The committee met on one single day with the members of the Executive Board (EB), some representatives of the Steering Committee (that were involved in the strategic process) and Scientific Advisory Board (SAB), and a selection of Management Board (MB) members. During this day the committee discussed the topics as mentioned above.

Based on the background documentation and the results from the interviews that were held during the review meeting, the review committee members have delivered a report including the strengths and weaknesses of JPND that have been identified.

Potential impact (including the socio-economic impact and the wider societal implications of the project so far) and the main dissemination activities and exploitation of results

Europe has a rapidly ageing population. Currently, 16% of the European population is over 65, and this figure is expected to reach **25%** by 2030.

Neurodegenerative diseases such as Alzheimer's and Parkinson's are debilitating and largely untreatable conditions that are strongly linked with age.

Amongst these disorders, the dementias are responsible for the greatest burden of disease, with Alzheimer's disease and related disorders affecting **over 7 million people in Europe**, and this figure is expected to double every 20 years as the population ages.

It currently costs approximately **€130 billion per annum** to care for people with dementia across Europe, highlighting age-related neurodegenerative disease as one of the leading medical and societal challenges faced by EU society.

Alzheimer's disease is particularly expensive to manage due to its insidious onset, its ever-increasing levels of disability and the length of time over which the condition extends itself. The average duration of this disease is between 2 and 10 years, during which patients will require special care that is a significant burden for both caregivers and for society as a whole.

While large investments have been made in other diseases such as cancer and cardio vascular disease (and we have consequently seen major improvements in treatment and patient outcomes), to date neurodegenerative diseases have not received the same level of funding, despite having a large negative impact on healthy life years.

Existing treatments for neurodegenerative diseases are very limited, and only treat the symptoms, rather than addressing the cause. In addition, no new drug treatment for Alzheimer's Disease has been approved in the past five years.

Potential impact

JUMPAHEAD helped build a new integrated way of collaboration within European countries. It will extend the European Research Area by mobilizing national and European resources toward common scientific goals. It fights fragmentation, and improve integration and coordination on national research programmes in the field of neurodegenerative diseases and Alzheimer's in particular. One expected impact is to increase the critical mass of researcher working on these fields to speed up discovery of new treatments and avoid redundancies. The ultimate goal of JUMPAHEAD is to lead to new initiatives around research excellence intended to offer a competitive and attractive image of European research prosecuted for the greatest benefit of Europe's populations and economies.

Impact on the Health Theme

The Coordination Action funded by the EC supported the country-led JPND initiative, which was the first of its kind. The JPND initiative aims to tackle the pan-European challenge facing all EU countries of our aging population and how this demographic change will lead to an exponential increase of neurodegenerative diseases, in particular Alzheimer's disease. The objectives of the JUMPAHEAD

project included the development of a Strategic Research Agenda, launched in February 2012, that prioritised questions in fundamental, clinical, and social research to be addressed during the lifetime of the participating countries joint initiative.

The first impact on the health theme was a defragmentation of the research on Neurodegenerative Diseases (ND) & Alzheimer's diseases (AD), through building of a common vision on the research priorities at European level and its implementation via existing and new instruments and actions. The coordination of research priorities directly impacts the Health theme by proposing instruments and domains reflecting needs with the potential of outputs with high impact. The implementation of the SRA should also improve the integration of disciplines and fields of research to develop linkages between basic, clinical and public health and social research. The third expected impact is the pooling and the coordination of national resources and efforts to reach the critical mass necessary to better understand, detect and prevent and combat basic mechanisms that trigger ND and to improve care service for people suffering from them.

Impact on the European Health Research community, i.e. on the different stakeholders involved in research

The impact on the European health research community will be huge as it will benefit from increased resources through pooling of resources from several member states. The strategy used to build the SRA is a bottom up one. Indeed, the SAB will be crucial to identify the fields to develop and the gap to bridge. The community will benefit also from the coordination at a European level of themes and topics to be addressed as a priority and also avoiding overlapped effort. This coordinated effort should also mean that bigger cohorts will be available at European level to research specific topics. During the period 2010-2014 eight joint transactional calls (including COEN initiative) were launched and 53 research projects are currently being funded for a total amount of more than 70 million €. The latest one was a Call for Proposals for Working Groups to Inform Cohort Studies in Neurodegenerative Disease Research, launched in 2014.

The impact on the European Health Research Community can therefore be described by the benefits and value each stakeholder is expected to get through the JUMPAHEAD coordination action. The key stakeholders include researchers/clinicians, policy makers and programme managers, patients and their family, and the general public.

Impact on the European Research Area (ERA)

The idea of a European Research Area grew out of the realisation that research in Europe suffers from three weaknesses: insufficient funding, lack of an environment to stimulate research and exploit results, and the fragmented nature of activities and the dispersal of resources.

To tackle this problem, the Commission proposed, in January 2000, the creation of a European Research Area. The initiative combines three related and complementary concepts:

- the creation of an "internal market" in research, an area of free movement of knowledge, researchers and technology, with the aim of increasing cooperation, stimulating competition and achieving a better allocation of resources;
- a restructuring of the European research fabric, in particular by improved coordination of national research activities and policies, which account for most of the research carried out and financed in Europe;
- the development of a European research policy which not only addresses the funding of research activities, but also takes account of all relevant aspects of other EU and national policies.

Despite this strong declaration of intent, only 5% of the total public funding of research is used in common among European countries through the 7th Framework Programme for Research and Technological Development, and about 10% to support intergovernmental schemes or organisations.

Conversely, 85% of these budgets are spent on national programmes exclusively, with probably less than 1% of the amount being reoriented to collaboration or coordination between countries.

As a consequence, individual national research programmes may unnecessarily duplicate each other from an international perspective. Despite having competences and skilled people within Europe and producing high quality research, when compared to the US research in Europe appears fragmented and much less efficient. One research field which appears among the most affected ones by a reduced level of investment, a high degree of fragmentation and a default of overall coordination is related to dementia and Alzheimer's disease.

This is why following the Commission's Communication on Joint Programming to tackle Europe's major societal challenges, the Competitiveness Council, called for a common commitment of EU Member States to fight Alzheimer's disease and other neurodegenerative diseases.

This coordination action helped build the ERA by fighting fragmentation, and improve integration and coordination on national research programmes in the field of neurodegenerative diseases, and in particular Alzheimer's.

Added value in undertaking the work at a European level

As in most fields of research, it is very difficult today for an isolated country to control at a very high level of skills and competences the wide variety of approaches required to decipher the highly complex patho-physiology of multifactorial diseases such as neurodegenerative and in particular Alzheimer's.

Translational research needs large cohort of patients that countries cannot afford on an individual basis. The development of high throughput screening in genomics, transcriptomics, proteomics and bioinformatics is based on larger and larger cohort to obtain the necessary statistical power to detect weak effects. Nine action groups were created to 1) determine transnational research needs and opportunities in the following priority areas and recommend the most appropriate approach to be adopted by JPND for implementation of each of these research priorities; 2) to promote engagement, commitment and partnership towards the implementation of specific priorities. In particular specific action group on longitudinal cohorts has delivered a report and a call for working groups was launched by JPND mid-2014 to address this issue.

Social health research will gain also from a European collaborative approach. Despite the strong relationships of social and health care questions with and country-dependent structures and culture, successful local solutions identified in some European countries may be analysed and transposed to other cultural context. Indeed, while hunting for new treatments, it is important to shorter term research into healthcare service organisation and delivery to help improve the impact of current approaches and the lives of both patients and carers. An action group on health and social care was formed in 2014 to address this topic.

Today most funding agencies working in their own countries and the top-down approach with a long lead in time from the Framework Programme do not allow rapid funding of innovative projects involving , for example, longitudinal studies of large cohorts. For instance Genome wide association study in Europe does not benefit of a large fund as the one developed by NIH in the US. Thus development of such projects relies on the willingness of individual researchers to set up complex financial plans to achieve their goals.

This JPND supported by JUMPAHEAD started to improve these situations. Thus only a structured European approach can address this major challenge by pooling and coordinating the efforts of basic and clinical researchers in this field. Obviously, joint programming can only be done at European level.

Most JPND member countries have no national roadmap or identified priority actions in the field of neurodegenerative disease research. Those member countries who do, take different approaches:

- Specific research programmes
- National plans targeted to an individual disease (e.g. Dementia)
- National plans comprising research, service delivery, or both

JPND is working to align specific areas of existing strategies relevant to neurodegenerative diseases, and also has a programme of actions aimed at encouraging countries to develop new research strategies.

Several countries are now processing strategic research agendas for neurodegenerative diseases (e.g. Denmark, Finland, Italy, Ireland). These national research strategies will both inform their countries' participation in JPND, and will focus resources on tackling neurodegenerative diseases nationally, aligning with the European Research Strategy.

Emerging national JPND-related strategies

Several new national strategies have made specific references to JPND and are seen as the national vehicles for participation in JPND:

- **The Netherlands**

Research is a major theme as part of the National Deltaplan for Dementia

“the Deltaplan will follow closely the JPND strategic research agenda and will strengthen the international position of the Netherlands for both research and industry”

Edith Schippers, Minister for Health, Welfare and Sport, The Netherlands

- **Ireland**

An Irish national SRA for neurodegenerative diseases has been developed to inform participation in JPND.

In addition, Irish researchers have used their participation in the JPND Alignment Action on biomarker optimisation to initiate a national network in biomarkers for Alzheimer's and Parkinson's.

- **United Kingdom**

David Cameron's “Prime Minister's challenge on dementia” includes specific references to continued support for COEN and JPND research

Account taken of other national or international research activities

The coordination action took into account the other national and international research activities and integrated them into the reflection for the SRA development and its implementation. This was a full part of JUMPAHEAD to ensure a rigorous mapping and to use as efficiently as possible the existing tools to achieve JPND goals. Specific JPND action groups are working to promote engagement, commitment and partnership towards the implementation of specific priorities.

Main dissemination activities and exploitation of results

To ensure that Joint Programming has an impact at EU level it was important that information on project outputs is disseminated to the right people in a timely manner.

The development and implementation of a two-way communication plan that takes into account the needs of stakeholders was crucial to inform this initiative and ensure its success. As this pilot joint programming initiative focuses on coordinating research efforts in the area of human health, the aim should be for the research funded to ultimately translate into benefits for patients, translating research into practise.

The area of neurodegenerative diseases and Alzheimer's research does not receive sufficient attention considering the negative impact it has on the healthy life expectancy of so many of our elderly citizens. However it is not be enough to simply fund more research: research needs to be

coordinated and prioritised according to the Strategic Research Agenda, and processes need to be developed so that results from this research reach the right end users. This is not a trivial task and is part of the “grand challenge” given the fragmentation of research efforts to date and the variety of funding systems and health care systems within the EU.

WP 4 Communication and Dissemination developed a plan for engaging effectively with different groups of stakeholders for the duration of the coordination action, and the plan can then be used for the lifetime of the joint programming initiative.

Depending on the information requirements for different groups of stakeholders, and their potential for engagement at different time points during the initiative, a range of dissemination methods were used in this plan.

The main outputs and results of JPND are new knowledge, ideas and understanding. Existing JPND online and offline resources and infrastructure provide information and ensure increased awareness of JPND and its supported projects. A number of JPND online tools and channels, including the JPND website (www.jpnd.eu) which attracts more than 50,000 unique visitors per annum, are available to disseminate JPND relevant information to relevant groups to facilitate knowledge transfer.

During JUMPAHEAD the dissemination achievements included:

- Publication of many articles in the press including Cell Journal, editorials in the Lancet Neurology, Nature magazine, etc.
- Availability of communication material such as flyer, poster, banner, etc.
- Presentation at conferences, organisation of roundtables and workshops. Such as the International Conference of Alzheimer Diseases International, the International Conference of Parkinson and Movement Disorders, the EU month of the Brain, the EU Joint Programming Conference, conference of Alzheimer Europe, etc.
- Publication of six-monthly newsletters, press releases at each important achievement of the project (launch of SRA, joint transnational calls etc.), website “News” items
- Group emails forwarded via the JPND stakeholder database (contact details of over 2000 individual stakeholders)
- Online video recording and interviews
- Dissemination through the social media channels such as twitter feed, Flickr, Slidshare, youtube.

In addition, the work performed within the JPND Action Groups is facilitating dissemination through the ongoing contacts being generated with industry, patient organizations and policy makers and will help to segment the target audiences and to tailor the message appropriately.

A detailed list of dissemination activities carried out during the project is available in the JUMPAHEAD final report.

Address of the project public website and relevant contact details

Public website: <http://www.neurodegenerationresearch.eu/>



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