



Recalibrated Monitoring and Evaluation Framework for the EU Joint Programme – Neurodegenerative Disease Research (JPND)

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**Abida Durrani
Work Package leader, Monitoring and Evaluation (ZonMw)**

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1. Introduction

This document contains two aspects of the monitoring and evaluation of the EU Joint Programme – Neurodegenerative Disease Research (JPND)¹, as delineated in the coordination action ‘Towards sustainability and globalisation of the Joint Programming Initiative on Neurodegenerative Diseases (JPsustaiND): (i) the recalibration of the monitoring and evaluation framework, including a set of performance indicators for JPND in general and JPsustaiND in particular and (ii) an adjusted questionnaire to be distributed amongst participating countries to investigate the attitudes towards and opinions of the initiative and the (perceived) effectiveness and usefulness of JPND. The information in this document builds on both the monitoring and evaluation framework for JPND that was developed in 2012 and the Grant Agreement-681043-JPsustaiND, taking into account the aims and objectives of JPsustaiND and the tasks defined in the different work packages.

JPsustaiND will build upon the existing monitoring and evaluation infrastructure that was developed in JUMPAHEAD by means of four specific tasks:

1. Recalibration and adjustment of the existing monitoring and evaluation framework of JPND (including performance indicators), especially taking into account the aim and specific objectives of JPsustaiND;
2. Annual monitoring exercises to follow up on the progress and performance of the initiative;
3. Investigation of the experiences, needs and expectations of the JPND research community in order to optimise (the process of) future calls for proposals;
4. Commissioning and coordination of an independent external evaluation of JPND as a whole.

The first task of the monitoring and evaluation work package consists of a process to recalibrate, refine and adjust the current JPND monitoring and evaluation framework.

For this task an adjusted intervention logic (logical framework) of JPND, including the indicators for performance was discussed in three Executive Board meetings in January, February and April 2016, in the Management Board meeting in Amsterdam in May 2016, and with JPsustaiND work package leaders. The feedback gathered during these meetings is taken into account in the *updated monitoring and evaluation framework*, developed as part of JPsustaiND, which integrates current and developing perspectives on JPND (sustainability, alignment and globalisation).

The first part of this document focuses on the monitoring and evaluation framework. This framework is based on a logical framework analysis of the JPND initiative which was developed in 2012 in close interaction with the Management Board members of JPND. (This is the methodological approach that supports the development of a monitoring and evaluation framework for JPND.)

The objectives of JPsustaiND are operationalised into a set of performance indicators that will be used in the monitoring and evaluation process.

It has to be mentioned beforehand that the monitoring and evaluation framework focuses on the JPND initiative as a whole. It is therefore not intended to monitor the individual work packages of the JPsustaiND project, although information from the individual work packages of this EU H2020 coordination action is included in the framework.

The second part of this document consists of an adjusted questionnaire that will be distributed amongst all members of JPND’s Management Board in Spring 2017 in order to investigate the attitudes towards and opinions of the initiative from a country and organisation’s perspective. The document ends with the planning of the JPND monitoring and evaluation process over the lifetime of JPsustaiND.

¹ More information about the initiative can be found at <http://www.neurodegenerationresearch.eu/>

2. JPND monitoring and evaluation framework

This chapter presents the monitoring and evaluation framework of JPND, based on its aims and intentions (2.1), the methodological approach used (2.2), the intervention logic of JPND / JPsustaiND (2.3), a list of proposed performance indicators that will be used for the monitoring and evaluation (2.4) and a brief overview of the information needed for the monitoring cycles and the midterm and final evaluation of JPND (2.5).

2.1. Aim of the monitoring, evaluation and impact assessment

The objectives of work package 6 (monitoring, evaluation and impact assessment), as defined in the JPsustaiND grant agreement are:

- to recalibrate the [existing monitoring and evaluation framework of JPND](#), which was developed in 2012, in order to meet the current focus of the initiative and the overall aim and specific objectives of JPsustaiND.
- to continue the on-going annual monitoring cycles of JPND's performance based on the defined set of performance indicators.
- to learn from the experiences of research communities that currently participate in projects and consortia supported by JPND-launched calls for proposals.
- to commission and coordinate an external evaluation of JPND, including an assessment of the (scientific and socioeconomic) impact of the programme to date.

Monitoring on the one hand focuses on the implementation of the programme and is oriented towards the inputs and direct outputs that are produced. Monitoring in the context of JPND consists of the on-going collection of information from the various activities (and work packages of JPsustaiND) to assist in the overall management of the initiative. Evaluation on the other hand is looking at the longer-term perspective by investigating the effects as indicated by short-term outcomes and scientific and socio-economic impacts. More detailed plans for the external evaluation will be developed in due course.

2.2. Indicators for measuring JPND's success

In 2012 a framework for monitoring and evaluation was developed and a set of performance indicators were identified for JPND and JUMPAHEAD based on a logical framework analysis of the JPND initiative. The approach is based on the idea that there is a linked chain of logic that shows how the activities of an intervention can be expected to produce immediate outputs connected to longer-term effects and eventually the realisation of the objectives (the impacts). This analysis was used to operationalise the concepts into a set of performance indicators for the monitoring and evaluation process.

JPsustaiND builds upon the existing monitoring and evaluation infrastructure that was developed in JUMPAHEAD and is adjusted to take into account the aims and specific objectives of JPsustaiND.

It has to be mentioned beforehand that the monitoring and evaluation framework focuses on the JPND initiative as a whole. It is therefore not intended to monitor the individual work packages of the JPsustaiND project, although information from the individual work packages of this EU H2020 coordination action is included in the framework.

The set of indicators used does not necessarily remain static during the lifetime of the initiative. Monitoring or evaluation may reveal the need for the adjustment of objectives. Some indicators may not be as useful as was originally thought. Sometimes proxy or indirect indicators are used when it is not possible to measure the effects of the initiative directly because needed data may not be available, or may be too difficult, sensitive or expensive to collect. Several indicators may also be brought together to make up indices of sub-indicators.

2.2.1. Types of indicators for JPND

As defined in the methodological report on monitoring and evaluation of JPND, indicators can be 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 (e.g. the amount of funding, human resources needed for the initiative).

- ❖ **Output indicators** relate to goods, services, technology and knowledge directly produced due to JPND activities (e.g. the number of European-wide population-based cohorts that are available for research).
- ❖ **Outcome indicators** show the initial results of the intervention, providing the reason for the programme and are less tangible than outputs (e.g. the number of preventive strategies that are in further development towards clinical use, or increased collaboration in research and research funding).
- ❖ **Impact indicators** measure the long-term socio-economic changes the intervention brings about (e.g. raised profile of research, and its contribution to treating neurodegenerative diseases).

Two types of indicators were identified following JPND's workplan and defined as:

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

2.3. The intervention logic of JPND / JPsustainND

Objectives of JPsustainND

The overall aim and objectives of JPsustainND are:

Overall aim is to build long-term sustainability for JPND, as a support for alignment and globalisation
The overall aim of JPsustainND is to support the development and extension of JPND capacities by creating a dedicated structure responsible for long-term JPND management and implementation. In doing so, these capacities will be extended globally and in particular to EU Member States not yet participating in JPND.

Objective 1: Explore possible scenarios for long-term sustainability by Member States, create political awareness to prepare their implementation, and develop and implement a dedicated structure responsible for long-term JPND management and implementation.

Objective 2: Extend the capacity of JPND beyond its current membership globally and in particular to EU Members States that do not yet participate in JPND and map the available resources for neurodegenerative disease research, by:

- Establishing collaborations with other initiatives or partners at the European and global levels;
- Extending the capacity and capabilities of JPND globally and to the missing EU-13 Member States and non-EU countries;
- Identifying available national research and innovation resources in the area of neurodegenerative diseases.

Objective 3: Alignment of national and JPND research strategy by developing and implementing:

- Strategies for further coordination of national and JPND research agendas;
- Initiatives to promote patient and carer perspectives;
- Initiatives for knowledge management, brokerage and transfer;
- Innovative strategies for the creation of infrastructures and tools that support international research activity;
- Novel strategies for industry-academia collaborations.

Activities

Since 2009, JPND has taken a number of major steps in order to fulfil its ambitious goals:

- Scientific integration, achieved through the adoption of a common Strategic Research Agenda, the JPND Research Strategy, coupled with a multiphase pluri-annual implementation, including large joint transnational calls supported by national funding only, and an ERANET co-fund call in 2015 with EC contribution;
- Managerial integration, achieved through an enshrined governance structure and binding, signed Terms of Reference and supported by a FP7-JUMPAHEAD coordination action (2010-2014);
- Financial integration, delivered through a virtual common pot where in-kind and in-cash contributions from participating countries can be combined, which provides an attractive and established model for EU contributions, as well as industrial and philanthropic funding.

While progress has been pleasing to date, the implementation of JPND will be scaled-up to further catalyse Member State commitments, and to formalize more precisely the synergies within members and various partners.

The following activities of JPND are already in place or foreseen for the future in order to address the objectives mentioned above.

On the level of process of joint programming (the policy level), JPsustaiND will maintain a structure for performing the coordination of different tasks in order to continuously orientate all activities towards the objectives and to ensure their fulfilment within time plan and budget. Other activities focussing on the policy level are:

- a. Development and implementation of a dedicated structure responsible for long-term JPND management and implementation.
- b. Establishment of collaborations with other initiatives or partners at the European and global level.
- c. Extension of the capacities of JPND globally including EU-13 missing Member States and non-EU member states.
- d. Alignment and capacity extension of research agendas in neurodegenerative diseases.
- e. Innovative strategies for the creation and alignment of infrastructures and tools.
- f. Creation of a communications network for the community of JPND stakeholders.
- g. Construction of a multi-lingual, Web 2.0-friendly, dissemination platform.
- h. Development of a specialist service for dissemination of neurodegenerative disease research progress to press and broadcast media.
- i. Identification of appropriate policy- and decision-makers at the EU and national levels and development of a plan that allows for effective engagement.
- j. Execution of the engagement plan using appropriate strategies and support of the plan in participating member countries.

On the scientific level the following activities are foreseen:

- k. Development of research performing long-term activities: leverage funding for calls.
- l. Development of an implementation plan for a knowledge hub for experimental models in neurodegenerative disease research, institutional programme funding and actions other than calls.
- m. Identification of available national research and innovation resources in the area of neurodegenerative diseases.
- n. Update of the JPND Research Strategy (SRA) for science and innovation.
- o. Alignment and capacity extension on health and social care research and development of knowledge-exchange mechanisms to obtain patient, carer and end-user perspectives within neurodegenerative diseases.
- p. Development of functional methodologies for the structuring of neurodegenerative disease research information for dissemination to target audiences.

Outputs

From the above proposed activities, the following outputs are anticipated.

The outputs related to the process of joint programming are:

- An increase in the number of researchers active in the field of neurodegenerative diseases and better collaboration in research (funding).
- An exploration of long-term sustainability of JPND.
- Raised awareness and potential extension of the JPND to the missing EU-13 Member States.
- Improved strategies for further coordination of national and JPND research agendas, and in particular for the take-up of JPND strategies and policies at the national level.

The scientific and societal outputs are an expansion of research activities focused at prevention, diagnosis and treatment. Furthermore JPND will contribute to the execution of European-wide population-based studies and information on the current state of neurodegenerative disease research. Networks of industrial and academic experts will also be built to boost industrial innovation in the field of neurodegenerative disease research in Europe.

Outcomes

An increase in the multiannual commitment of JPND member countries, the long-term sustainability of the JPND research and innovation strategy, and a long-term structuring effect to mobilize the

necessary and critical mass are expected. Furthermore, an increase in the efficiency of research and innovation investments by European Member States by avoiding duplication of research and infrastructure investment at the national level is also expected. The coordination and integration of national research & innovation programmes with the JPND research strategy is in coherence with Horizon 2020 objectives.

On the scientific and societal level there will be better integration of basic, clinical and healthcare research and a more effective transdisciplinary approach. Also there will be an increase in innovative diagnostics, preventive strategies and therapies in clinical pipelines and improved strategies for the creation of infrastructures and tools to facilitate the more rapid uptake of data and methodologies for research on neurodegenerative diseases in the EU and beyond.

Impact

JPND is considered to be a model for future research collaboration in Europe (and beyond). JPND will be able to further establish itself as a reference for European and global knowledge and as an innovation platform in the area of neurodegenerative diseases. Also there will be an increase in neurodegenerative disease research capacity and associated investments in European research for these diseases.

On the scientific and societal level there will be an increased understanding of the detection, prevention and treatment of neurodegenerative diseases. A raised profile of neurodegenerative diseases and an increased visibility of the burden of these diseases at the political level are also expected. The impacts on health care costs, better care for people suffering from these diseases improved quality of life for patients are also expected but are difficult to measure during the lifetime of JPND as these impacts are sometimes hard to attribute to the initiative and the outputs and outcomes of projects supported by JPND may need some time to be implemented in policy and practice.

2.4. JPND performance indicators

Taking the objectives of JPsustainND (2015 – 2019) into account an updated monitoring and evaluation framework is presented below.

The tables provide the final set of performance indicators, with a distinction between type A and type B indicators and the different indicator categories (input, output, outcome and impact). For each main objective and sub-objective indicators are described. It should be noted that the category output, outcome and impact indicators attributed per sub-objective can be a result of wider input / activities performed for the different objectives of JPsustainND. Although a couple of outcome and impact indicators are defined, in the context of monitoring the progress of JPsustainND the focus will be on the input and output indicators. This is because outcomes and impacts need some time to occur and are sometimes hard to attribute to the initiative. These longer-term effects will be taken into account as far as possible in the midterm (month 20) and final evaluation of the JPsustainND project.

2.4.1. Overview of performance indicators

Table 1 and Table 2 provide the proposed list of indicators. In Annex 1 the defined set of indicators are further specified in terms of reference to the source that will be used to measure the indicators.

Type A indicators

Table 1: Type A indicators to monitor the effect of JPND on (European) research programming, research policy and funding (the concept of joint programming) related to the objectives of JPsustainND.

Objectives JPND / JPsustainND	Input	Output	Outcome	Impact
1. Explore possible scenarios for long-term sustainability by Member States, create political awareness to prepare their implementation, and develop and implement a dedicated structure responsible for long-term JPND management and implementation				
1.1. Develop and implement a dedicated structure for long-term JPND management	1 Participation grade of Member States in Management Board meetings 2 Attitude of JPND Members towards JPND goals and objectives 3 Opinion on the progress and anticipated results of JPND 4 The dropout of countries 5 Well-defined, adequate and functional structures (tasks of governance body and terms of reference for the Joint Actions) and procedures (description of work, collaboration between the governance) 6 Opinion on the defined structure and procedures for long-term JPND management	15 Agreement on organisational structure for long-term JPND management 16 Business plan for long-term JPND management is finalized 17 Participation grade of Member States in the dedicated structure and the degree of interest in the dedicated structure	20 Creation of a legal entity for long-term JPND management 21 (Increase in) financial commitment of Member States for future partnership (6 years of more)	
1.2. Adequate and functional structures and procedures for (long-term) JPND management	7 Opinion on description of tasks in CSA 8 Opinion of MB on MoUs and ToR 9 Opinion of MB on the process and content of MB meetings			

Objectives JPND / JP sustainND	Input	Output	Outcome	Impact
1.3 Develop research performing long-term activities	<p>10 The number of new joint transnational calls for proposals</p> <p>11 The number of new initiatives for co-funding programmes with the EC</p> <p>12 The number of researchers/teams applying to JPND calls</p> <p>13 The success rate of granted projects versus the number of applications</p>	18 The amount of multi-annual commitments (in terms of earmarked budget) and number of calls and projects supported		
1.4 Initiatives for non-project funded activities	14 The number of new initiatives for non-project funded activities	19 Allocated funding through joint transnational calls for proposals and non-project funded activities (e.g. workshops, symposia etc.)		
2. Extend the capacity of JPND beyond its current membership globally, including the EU Members States that do not yet participate in JPND and map the available resources for neurodegenerative disease research				
2.1. Extend the capacity of JPND globally, and to EU 13 missing Member States and non-EU Member States	22 The number of new EU (i.e. 13 missing Member states) and non-EU (i.e. third countries) joining / participating in JPND activities			24 Investment in European R&D in neurodegenerative disease research as share of total investment in R&D
2.2. Establish collaborations with other initiatives or partners at the European and global levels	23 The number of new collaborative activities commenced with non-JPND member organizations			
3. Alignment of national and JPND research strategies				
3.1. Alignment and capacity extension of research agendas in neurodegenerative diseases		<p>27 Number of meetings and participation grade of Member States in working groups on alignment</p> <p>28 The national research (funding) priorities adapted as a result of JPND and the (scientific) priorities identified in the JPND Research Strategy</p>	<p>32 Changes in national research priorities</p> <p>33 Changes in research priorities of national agencies</p>	36 The number of publications in high-impact journals by researchers supported by JPND as a share of the rest of the world in neurodegenerative disease research
3.2: Alignment and capacity extension on health and social care research and development of knowledge		<p>29 Alignment of national research funding programmes</p> <p>30 New or updated country strategies</p>	34 The amount of JPND common research funding for neurodegenerative diseases as share of total EU research funding	

Objectives JPND / JPsustaiND	Input	Output	Outcome	Impact
exchange mechanisms to obtain patient, carer and end-user perspectives within neurodegenerative diseases		that mirror the impact of JPND	35 The total amount of European funding available for neurodegenerative disease research	
3.3. Innovative strategies for the creation and alignment of infrastructures and tools	25 Harmonised rules and procedures for participation 26 Coordination of timing in funding and programme implementation	31 Opinion on whether JPND contributed to harmonised funding research in the field of ND		
4. Communication and advocacy with the aim of developing a sustainable infrastructure and web-based platform, accessible to citizens and stakeholders.				
4.1 Develop a sustainable infrastructure and web-based platform, accessible to citizens and stakeholders, for communicating the outputs of JPND-supported research and actions	37 Communication strategy has been documented 38 Expand current website into a multilingual online platform	43 The number of unique visits to JPND website, number of followers / subscribers to JPND news feeds/social media, JPND search engine ranking		
4.2 Ensure awareness of the importance of JPND among policy-making stakeholders at the European and national levels	39 Host at least three specific engagements/events targeting policy-making stakeholders at the European and national levels over the lifetime of JPsustaiND 40 A JPND Advocacy plan targeting policy makers at the EU and national levels	44 The number of generalised and specialized media hits and press articles to raise awareness and potential extension of JPND 45 Increased number of policy-making stakeholders in JPND stakeholders database		
4.3 Engage with appropriate stakeholders at appropriate times throughout the initiative	41 Annual conferences, workshops and seminars 42 Incorporate appropriate stakeholders into the JPND communications infrastructure via the Information Management Team, which will be created under JPsustaiND	46 Integration of appropriate stakeholders and stakeholder concerns into JPND communications content		

Type B indicatorsTable 2: Type B: *indicators* regarding the scientific and societal impact of JPND research in the field of neurodegenerative diseases

Objectives JPND / JPsustainND	Input	Output	Outcome	Impact
1. Explore possible scenarios for long-term sustainability by Member States, create political awareness to prepare their implementation, and develop and implement a dedicated structure responsible for the long-term JPND management and implementation.				
1.1 Develop research performing long-term activities	1 The number of collaborative research projects funded through JPND joint calls that address the scientific priorities identified by JPND	-	4 The number of European-wide population-based studies with a contribution from JPND 5 The number of scientific publications in highly ranked journals focusing on prevention, diagnosis and treatment resulting from JPND supported projects	-
	2 The number of non-project funded activities that address the scientific priorities identified by JPND	-	-	-
1.2 Implementation plan for a collaboration platform (knowledge hub) where members connect, discuss, exchange knowledge and develop initiatives to improve research on ND	3 Variety of actions and instruments used for the implementation plan for a collaboration platform	-	6 Regular interaction between JPND and researchers	-
2. Extend the capacity of JPND beyond its current membership globally, including to the EU Members States which are not yet participating in the JPND and map the available resources for neurodegenerative disease research				
2.3 Identify available national research and innovation resources in the area of neurodegenerative diseases.	-	7 The existence of an up-to-date overview of neurodegenerative disease research programmes and initiatives 8 Updated JPND Research Strategy for science and innovation 9 The existence of a web portal that provides access to high level information on available cohort studies of value for neurodegenerative disease	11 Satisfaction of researchers about accessibility and availability of information by means of web portal	-

Objectives JPND / JPsustaiND	Input	Output	Outcome	Impact
		research 10 Updated JPND searchable database on the scope and spread of research related to neurodegenerative diseases		
3. Alignment of national and JPND research strategies				
3.2. Alignment and capacity extension on health and social care research and development of knowledge exchange mechanisms to obtain patient, carer and end-user perspectives within neurodegenerative disease	-	-	13 The number of products (e.g. guidelines, protocol standards, changes in professional practice) applied in policy and practice as a result of granted JPND supported projects 14 Regular interactions between JPND and stakeholder groups (patient organisations, healthcare practitioners, industry)	16 Exchange of (best) practices across different types of research (basic, clinical and healthcare)
3.3 Innovative strategies for the creation and alignment of infrastructures and tools	-	12 Innovative strategies to facilitate wider access to technology platforms and infrastructures such as biobanks, informatics capabilities and neuroimaging	15 Number of interactions with relevant EU groups (ESFR!) or international networks	-

2.5. Collection of information for monitoring and evaluation

To collect the information needed for the monitoring and evaluation process, different sources will be consulted:

- The minutes of the Management Board meetings and information about the countries' attendance and other information (to be found on JPND's extranet, supported by the JPND Secretariat, WP1).
- The composition and minutes of the different working groups (to be provided by the working group chairs, supported by the JPND Secretariat, WP1).
- Information on the supported projects in the joint calls for proposals and the annual reports of the supported projects (Joint Call Secretariat, WP2).
- Information on the progress of the mapping exercise (WP3).
- Information on alignment and capacity extension of research agenda's in neurodegenerative disease research (WP4).
- Information on outreach and communications activities (WP5).
- The questionnaire distributed to Member State representatives (monitoring team, WP6) (see Chapter 3).

3. Questionnaire JPND

This questionnaire is an update of a questionnaire on attitudes towards JPND that was validated in 2012. The questionnaire is adjusted as part of the monitoring exercise of JPsustainD. Question nr. 8, 10, 16, 19, 20, 21, 27 and 28 are added. In questions 9, 15, 22 and 23 small changes are made.

This questionnaire will be distributed in March 2017 amongst all participating member states of JPND to investigate their current attitudes towards the JPND initiative and the (perceived) effectiveness and usefulness of JPND. A first survey was conducted in 2012, of which the results were fed into the first JPND monitoring report. The results of the second questionnaire will contain among others identified changes in the countries' perceptions and attitudes towards the programme.

This questionnaire focuses on the expectations, motivations and foreseen effects of JPND both within the organisation itself and within the national research-funding context. It also contains questions focusing on the current functioning of JPND and the achievements thus so far. The questionnaire will address issues such as possibilities to mobilise national funding for JPND and to align national programmes with programmes in other countries, the feasibility of executing collaborative projects within the JPND framework, the sustainability of JPND and the expected benefits of JPND relative to other EC programmes.

The questionnaire is divided into seven main blocks:

1. General information on the type of organisation and the involvement in JPND
2. Attitudes towards the goals and objectives
3. Expectations for taking part in JPND
4. Opinions on current JPND activities
5. Opinions on the governance structure of JPND
6. Achievements so far
7. Expectations for the future

For each country, the Management Board representatives will be contacted by means of an online questionnaire, utilising a professional survey facility (Monkey survey), which is regularly used for surveys conducted at the national and European level. This survey tool allows us to design the appearance and behaviour of the questionnaire, issue the requests to prospective survey participants, track their responses individually, and analyse the results within a single dedicated environment.

The service provides considerable functionality, avoids any duplication of effort and is both reliable and secure.

We suggest that the respondents and the information they provide be identifiable, instead of collecting the results anonymously.

This is because it will allow us to track how expectations and opinions have evolved for specific members/countries.

Questionnaire introduction

In an introductory text the purpose of this questionnaire will be explained to the country representatives (the Management Board members). The topics that are addressed are introduced as well, as are the way the responses are collected and analysed (to make it clear that respondents will be anonymous). The time frame for the collection of the responses (beginning of March – mid April 2017) will also be explained.

2.1. General information

Please provide us with information that characterises you, the country and organisation you represent in the Management Board of JPND.

1. Name
2. Function
3. Which country do you represent in the Management Board of JPND? [Drop down menu of all participating member states with functionality to expand if new members would join]
4. Please select the type of organisation you represent in the Management Board of JPND:
 - ❖ Ministry (e.g. Education, Economy, Science and Innovation, Health, etc.).
 - ❖ Research funding organisation (research councils or agencies).
 - ❖ University or university medical centre.
 - ❖ Public research centre.
 - ❖ Intermediary organisation.
 - ❖ Other... (please specify)
5. Since when have you personally been a member of the Management Board of JPND? [In case the respondent just recently joined the MB as a result of replacement, the previous representative will be contacted as well in order to get better results. A drop down menu with date options will be given]
6. If you recently joined the Management Board (i.e. you joined less than 4 months ago) as a result of replacement, could you please enter the name and e-mail address of your predecessor?
7. Are you involved in one of the JPND working groups that were set up to implement JPND's Research Strategy? [No, Yes with drop down menu containing the working groups]
8. Describe the level of your country's participation in JPND.
You should in particular refer to both existing and planned 'in-kind' and actual financial contributions as well as to the situations where your country is present as observer.
9. Is your organisation also actively involved in any of the following (funding) initiatives?
 - ❖ ERA-NETs or ERA-NETs +
 - a. FP6 - NEURON (Network on European Funding for Neuroscience Research).
 - b. FP7 - ERA-instruments (Infrastructure Funding in the life sciences).
 - c. FP7 - EUROCOURSE (Europe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research).
 - d. FP7 - EuroNanoMed (European network of trans-national collaborative RTD projects in the field of NANOMEDicine).
 - e. FP7 - EUROTRANSBIO (European programme for TRANS-national R&D&I cooperations of BIOTech SMEs).
 - f. EraNETplus - ERASysBio+ (The consolidation of systems biology research - stimulating the widespread adoption of systems approaches in biomedicine, biotechnology, and agri-food).

- g. EraNetplus - NanoSci-E+ (Transnational call for collaborative proposals in basic nanoscience research).
 - h. FP6 - PathoGenoMics (Trans-European cooperation and coordination of genome sequencing and functional genomics of human-pathogenic microorganisms) (for discussion).
 - i. FP7 - ERA-ENVHEALTH (Coordination of national environment and health research programmes - Environment and Health ERA-NET) (for discussion).
 - j. Horizon2020 – ERA-NET Cofund (Transnational call for collaborative proposals on longitudinal Cohort Approaches, Advanced Experimental Models and Risk and Protective Factors neurodegenerative diseases).
 - k. Article 185 – AAL.
 - l. Other... (please specify)
 - ❖ European Innovation Partnership on Active and Healthy Ageing.
 - ❖ Joint Actions.
 - ❖ Innovative Medicines Initiative (IMI).
 - ❖ Ambient Assisted Living Joint Programme (AAL JP).
10. Does your organisation make use of European Regional Development Fund for JPND? If yes, please describe the level of use?

2.2. Attitude towards the goals and objectives

11. Could you please give your opinion on the relevance of JPND goals and objectives by means of answering the following set of statements (Agree – Disagree – Undecided)
- ❖ Identification of common goals that would benefit from joint actions.
 - ❖ Establishment and alignment of national research programmes with the JPND research strategy.
 - ❖ Creation of critical mass of research capacity (clinicians and translational scientists).
 - ❖ Development of framework for integrated approach in basic, clinical and healthcare research.
 - ❖ Development of novel research tools and infrastructures for neurodegenerative diseases.
 - ❖ Implementation of experiences into evidence-based policies and best-practices.
 - ❖ Establishment of Europe-wide population-based longitudinal studies.
 - ❖ Development of animal and cell-based models.
 - ❖ Development of new diagnostic criteria, biomarkers and treatments.
 - ❖ Promotion of research in non-specialist setting.
 - ❖ Stimulation of education and training of healthcare professionals.
 - ❖ Destigmatisation of patients.
 - ❖ Raising awareness of the importance of research on neurodegenerative diseases.

2.3. Expectations for taking part in JPND

This section deals with your (country's) expectations towards JPND, both on the level of your organisation and in the national funding context.

12. What were the motivations for your organisation to join JPND? [five-points rating scale: Unimportant – Of Little Importance – Moderately Important – Important – Very Important]
- ❖ To be better informed about the research on neurodegenerative diseases that is taking place in other countries.
 - ❖ To coordinate the thematic contents of our national research strategies and priorities to be more in line with similar research initiatives in other EU countries.
 - ❖ To coordinate the thematic contents of our research priorities and funding with those of other EU countries...
 - ...with the aim of thematically focusing our own research (funding) activities.
 - ...to identify 'white spots' that could be of interest to our national researchers.
 - ...to decide on a division of labour in research themes between EU countries.
 - ...so that funding resources are pooled and we can increase the scale of research.
 - ❖ To increase the funding for research on neurodegenerative diseases in my country.
 - ❖ To increase the funding for research neurodegenerative diseases in the whole of Europe.
 - ❖ To leverage funding from the European Commission.
 - ❖ To be able to attract excellent researchers to our national programmes.
 - ❖ To benefit from access to patient and research data across the countries participating in JPND.
 - ❖ To have a common voice vis-à-vis non-European countries (for collaboration).
 - ❖ To know which new ND research initiatives to start in my country.
 - ❖ To know which ND research initiatives to terminate in my country.
 - ❖ To give our national researchers access to research funding outside our country.
 - ❖ To allow the national researchers to work more closely with excellent researchers in other EU countries.
 - ❖ To benefit from open access of research infrastructures across the JPND countries.
 - ❖ Other... (please specify)
13. Of the motivations listed above, where do you expect JPND to have the largest impact in two years from now? [tick box with a maximum of three options] Please explain.
14. The collaborative projects within the JPND framework funded via joint calls will have a higher chance of achieving concrete results than projects funded on a national level or within European Community research programmes? [Strongly Agree – Agree – Undecided – Disagree – Strongly Disagree]
15. If your organisation actively participates in any other European initiatives such as ERA-nets, the European Innovation Partnership on Active and Healthy Ageing and Joint Actions, to what extent is JPND aligned with these initiatives? [Good, Fair, Poor]

2.4. Opinions on current JPND activities

This part of the questionnaire focuses on the activities that are currently implemented within the JPND initiative.

16. Could you please give your opinion on the JPND activities by means of answering the following set of statements? [Strongly Agree – Agree – Undecided – Disagree – Strongly Disagree]

- ❖ JPND's Research Strategy includes the most urgent research priorities.
- ❖ The JPND initiative already raised awareness in my organisation regarding the importance of neurodegenerative diseases.
- ❖ Our country already started with the implementation of JPND's Research Strategy on a national level (please explain in what way).

16. Regarding the JPND work plan, how satisfactory have the following procedures been (scale of 1 to 5; 1 – very unsatisfactory, 5 – very satisfactory)

- a) Transnational call procedures
 - The selection process.
 - The success rate in comparison to internal call or EU calls.
 - The administrative burden.
 - The ability to attract high quality researchers.
 - dissemination of the calls and project outcomes (webpage, newsletter, webinars, networks).
- b) Seminars and scientific networking.
- c) Communication between partners.
- d) Progress of the Work Packages in general.
- e) Other, please specify

Comments:

17. On average, how much of your time did you spend on JPND during the last 6 months? [More than two days a week – Between one day and two days a week – One day a week – Half a day a week – Less than half a day a week]

18. Do the additional transaction costs of JPND outweigh the foreseen benefits? [Strongly Agree – Agree – Undecided – Disagree – Strongly Disagree]

2.5. Opinion on the governance structure of JPND

This part of the questionnaire focuses on the governance structure of the JPND initiative.

19. Could you please give your opinion on the JPND activities by means of answering the following set of statements? [Strongly Agree – Agree – Undecided – Disagree – Strongly Disagree]

- ❖ The description of the governance structure of JPND / JPsustaiND is clear.
- ❖ The governance structure of JPND / JPsustaiND is constructive.
- ❖ The description of work was a good tool to structure working processes.
- ❖ The transition between different JPND projects (JPsustaiND and JPco-fuND) is clear.

- ❖ Memorandum of Understandings (MoU's) and Terms of References (ToR) for the different Joint Actions gives well described guidelines for the participating Member States.
- ❖ The Management Board Meetings are constructive in relation to the process.
- ❖ The Management Board Meetings are constructive in relation to the content.

2.6. Achievements so far

This part of the questionnaire focuses on the achievements due to participation in JPND since its launch in 2010.

20. Please rank the outputs that in your opinion have occurred after participating in JPND so far (1=heavily occurred; 2= moderately occurred - 3 = slightly occurred; 4=not occurred; 5 = no opinion).

- ❖ Increase in the number of researchers working on neurodegenerative diseases in my country.
- ❖ Grouping of knowledge (more collaboration between researchers in the field of neurodegenerative diseases).
- ❖ Cross-border funding calls (more coordination and alignment between national funding organisations in neurodegenerative diseases).
- ❖ Better collaboration in sharing of research infrastructures.
- ❖ Expansion of current research activities.
- ❖ Increase in other funding activities on neurodegenerative diseases other than research.
- ❖ Development of either formal or informal national research strategy (based on JPND's Research Strategy).
- ❖ Alignment of research topics between individual countries.
- ❖ Contribution to European-wide population-based studies.
- ❖ Establishment of patient cohorts.
- ❖ Information about the current state of neurodegenerative diseases research.
- ❖ Other (please specify)...

21. What are in your opinion the (socio-economic) impacts that JPND has effected (or at least contributed to)?

- ❖ JPND is considered to be a model for future research collaboration with respect to other JPI's.
- ❖ An increase of the investments in European research in the field of neurodegenerative diseases.
- ❖ An increase in the profile of neurodegenerative disease research.
- ❖ An increased understanding of the detection, prevention and treatment of neurodegenerative diseases.
- ❖ Contributed to a reduction of healthcare costs.
- ❖ Better care for people with neurodegenerative diseases.

- ❖ Raised profile of neurodegenerative diseases among policy makers.
- ❖ Increased visibility of the burden of disease at the political level.

2.7. Expectations for the future

This last part of the questionnaire focuses on your expectations for the future of JPND.

22. Please rank the outputs that in your opinion are most likely to occur within the coming three years of JPSustaiND (i.e. the lifetime of the JPSustaiND project) (1 = most likely to occur, 10 = less likely to occur).

- ❖ Increase in the number of researchers working on neurodegenerative diseases in my country.
- ❖ Grouping of knowledge (more collaboration between researchers in the field of neurodegenerative diseases).
- ❖ Grouping of funding calls (more coordination and alignment between national funding organisations).
- ❖ Better collaboration in sharing of research infrastructures.
- ❖ Expansion of current research activities.
- ❖ Development of either formal or informal national research strategy (based on JPND's Research Strategy).
- ❖ Alignment of research topics between individual countries.
- ❖ Contribution to European-wide population-based studies.
- ❖ Establishment of patient cohorts.
- ❖ Information about the current state of neurodegenerative diseases research.
- ❖ Other (please specify)...

23. What do you consider the most important longer-term effects (5 years and beyond) of JPND? Please indicate your top-3.

- ❖ An increase in focus of scientific research towards strategic objectives in the field of neurodegenerative diseases among EU Member States.
- ❖ Financial commitment of Member States for future partnership (6 years or more).
- ❖ An increase in the amount of research funding in the field of neurodegenerative diseases.
- ❖ A reduction of duplication and fragmentation of research activities.
- ❖ Better integration of basic, clinical and healthcare research.
- ❖ A more effective transdisciplinary approach.
- ❖ New diagnostics, preventive strategies and therapies in the clinical pipeline.
- ❖ Reduction of stigmatised patients.
- ❖ Other... (please specify)

24. Please rank the (socio-economic) impacts that in your opinion JPND is likely to bring about (or at least contribute to)? (0-5 years, 6-10 years, 11-15 years, 15 years and beyond)

- ❖ JPND will be considered to be a model for future research collaboration.
- ❖ An increase of the investments in European research in the field of neurodegenerative diseases.
- ❖ An increased understanding of the detection, prevention and treatment of neurodegenerative diseases.
- ❖ Contribution to a reduction of healthcare costs.
- ❖ Better care for people with neurodegenerative diseases.
- ❖ Raised profile of neurodegenerative diseases.
- ❖ Increased visibility of the burden of disease at the political level.

25. Where do you want JPND to be in 5 years? [Not very likely – Maybe – Very Likely]
JPND will...

- ❖ ...be a self-organising funders network with mostly the same member states.
- ❖ ...be a self organising network with a smaller number of member states.
- ❖ ...will issue at least two large calls a year.
- ❖ ...have updated and amended its SRA.
- ❖ ...will have developed a 'common pot' of funding that is allocated regardless of the geographical location of the researchers.
- ❖ ...will have triggered an increase in public funding for research on neurodegenerative diseases of at least 25%.
- ❖ ...will have attracted considerable interest from the private sector.
- ❖ ...will have a share of at least 25% of its funding from the private sector.
- ❖ ...will have led to the development of important biomarkers.
- ❖ Other... (please specify)

26. What kind of activities should JPND focus on in the future? [100% to be allocated to each of the following aspects]

- ❖ Joint calls for proposals.
- ❖ Education and training of researchers.
- ❖ Exchange programmes for researchers.
- ❖ Mobility programmes for researchers.
- ❖ Creation of research infrastructures.

- ❖ Exchange programmes between researchers and other stakeholders (e.g. policy workers, healthcare practitioners, industry, etc.).
- ❖ Other... (please specify)

27. Under what conditions can your organisation continue to participate in transnational activities in the European Research Area for neurodegenerative diseases beyond the lifetime of JPsustainND (include only in the last survey: 2017).

- a. Can only continue with the current level of EU-funding.
- b. Can continue with reduced EU-funding.
- c. Can continue with more EU-funding.
- d. Can continue without EU-funding (self-sustained).

28. The expectations on the project's development will be a crucial element to strengthen this transnational network made up of partners with different motivations and levels of commitment. Do you expect obstacles for general cooperation within JPsustainND?

Yes, if yes please specify (e.g. turnover of personnel, lack of competencies, etc.)

No.

2.8. Concluding remarks

29. Please leave any additional remarks or other feedback in the text box below.

4. Planning of the JPsustaiND monitoring and evaluation process

The table below gives an overview of the time frame for the monitoring and evaluation process over the next four years (i.e. over the lifetime of the JPsustaiND project).

After the recalibration of the monitoring and evaluation framework of JPND has finished, one monitoring cycles is foreseen during the course of JPsustaiND, with a monitoring report. The monitoring report, delivered in month 20 present the current performance of the programme by addressing the indicators that have been defined, in particular the input and output indicators and, in cases where already possible, outcome indicators. It will also include the results of an electronic questionnaire (month 16: March 2017), which will be distributed amongst participating JPND countries. A first questionnaire was conducted in 2012, the results of which fed into the first JPND monitoring report. The results of this second questionnaire will contain similar questions to identify changes in the countries' perceptions and attitudes towards the programme.

Monitoring activities of JPND are performed during the entire duration of JPsustaiND, as it provides input for the external evaluation that will be conducted close to the end of the project (months 32 to 40).

Table 3: Planning of the monitoring and evaluation process

Deliverables	2016				2017				2018				2019			
	Q 1	Q 2	Q 3	Q 4	Q 1	Q 2	Q 3	Q 4	Q 1	Q 2	Q 3	Q 4	Q 1	Q 2	Q 3	Q 4
Recalibrated monitoring and evaluation framework (D6.1)		X														
Monitoring report 1 (D6.2)						X										
Report on researchers' opinions regarding JPND calls for proposals processes (D6.3)									X							
External evaluation report of JPND's performance (D6.4)														X		

Annex 1: Goals, performance indicators and sources

Table 4: Type A indicators to monitor the effect of JPND on (European) research programming, research policy and funding (the concept of joint programming) related to the objectives of JPsustainD.

Type A Performance indicators	Source (how to measure)	How often to be measured
I. Long-term sustainability		
1 Participation grade of Member States in Management Board meetings	Minutes Management Board (MB)	Midterm (2017) and final evaluation
2 Attitude of JPND Members towards JPND goals and objectives	Survey MB (see Q ...)	Midterm (2017)
3 Opinion on the progress and anticipated results of JPND	Survey MB	Midterm (2017)
4 The dropout of countries	Survey MB	Midterm (2017) and final evaluation
5 Well-defined, adequate and functional structures (tasks of governance body and terms of reference for the Joint Actions) and procedures (description of work, collaboration between the governance)	Annual report WP2 / Minutes MB	Midterm (2017) and final evaluation
6 Opinion on the defined structure and procedures for long-term JPND management	Annual report WP2 / Survey MB	Midterm (2017)
7 Opinion on description of tasks in CSA	Survey MB	Midterm (2017)
8 Opinion of MB on MoUs and ToR	Survey MB	Midterm (2017)
9 Opinion of MB on the process and content of MB meetings	Survey MB	Midterm (2017)
10 The number of new joint transnational calls for proposals	Annual report WP2	Midterm (2017) and final evaluation
11 The number of new initiatives for co-funding programmes with the EC	Annual report WP2	Midterm (2017) and final evaluation
12 The number of researchers/teams applying to JPND calls	Annual report WP2 / Minutes MB meetings	Midterm (2017) and final evaluation
13 The success rate of granted projects versus the number of applications	Annual report WP2	Midterm (2017) and final evaluation
14 The number of new initiatives for non-project funded activities.	Annual report WP2	Midterm (2017) and final evaluation
15 Agreement on organisational structure for long-term JPND management	Annual report WP2	Final evaluation
16 Business plan for long-term JPND management is finalized	Annual report WP2	Final evaluation
17 Participation grade of Member States in the dedicated structure and the degree of interest in the dedicated structure	Annual report WP2 / Minutes MB	Midterm (2017) and final evaluation
18 The amount of multi-annual commitments (in terms of earmarked budget and number of calls and projects supported.	Annual report WP2	Midterm (2017) and final evaluation
19 Allocated funding through joint transnational calls for proposals and non-project funded activities (e.g. workshops, symposia etc.)	Annual report WP2	Midterm (2017) and final evaluation
20 Creation of a legal entity for long-term JPND management	Annual report WP2	Final evaluation
21 (Increase in) financial commitment of Member States for future partnership (6 years of more)	Annual report WP2	Midterm (2017) and final evaluation
II. Capacity extension of JPND beyond its current membership		
22 The number of new EU (i.e. 13 missing Member states) and non-EU (i.e. third countries) joining / participating in JPND activities	Annual report WP3	Midterm (2017) and final evaluation
23 The number of new collaborative activities commenced with non-JPND member organizations	Annual report WP3	Midterm (2017) and final evaluation
24 Investment in European R&D in neurodegenerative disease research as share of total investment in R&D.	Annual report WP3	Midterm (2017) and final evaluation

Type A Performance indicators	Source (how to measure)	How often to be measured
III. Alignment of national and JPND research strategies		
25 Harmonised rules and procedures for participation	Annual report WP3	Midterm (2017) and final evaluation
26 Coordination of timing in funding and programme implementation	Annual report WP3	Midterm (2017) and final evaluation
27 Number of meetings and participation grade of Member States in working groups on alignment.	Annual report WP3	Midterm (2017) and final evaluation
28 The national research (funding) priorities adapted as a result of JPND and the (scientific) priorities identified in the JPND Research Strategy.	Annual report WP4 / Minutes working groups on alignment	Midterm (2017) and final evaluation
29 Alignment of national research funding programmes	Annual report WP4	Midterm (2017) and final evaluation
30 New or updated country strategies that mirror the impact of JPND	Annual report WP4	Midterm (2017) and final evaluation
31 Opinion on whether JPND contributed to harmonised funding research in the field of ND	Annual report WP4 / Survey MB	Midterm (2017) and final evaluation
32 Changes in national research priorities.	Annual report WP4 / Survey MB	Midterm (2017) and final evaluation
33 Changes in research priorities of national agencies.	Annual report WP4 / Survey MB	Midterm (2017) and final evaluation
34 The amount of JPND common research funding for neurodegenerative diseases as share of total EU research funding	Annual report WP3 / WP4 / Survey MB	Midterm (2017) and final evaluation
35 The total amount of European funding available for neurodegenerative disease research	Annual report WP3, WP4 / Survey MB	Midterm (2017) and final evaluation
36 The number of publications in high-impact journals by researchers supported by JPND as a share of the rest of the world in neurodegenerative disease research	Annual report WP2 / Bibliometric study	Midterm (2017) and final evaluation
IV. Communication and advocacy		
37 Communication strategy has been documented	Annual report WP5	Midterm (2017) and final evaluation
38 Expand current website into a multilingual online platform	Annual report WP5	Midterm (2017) and final evaluation
39 Host at least three specific engagements/events targeting policy-making stakeholders at the European and national levels over the lifetime of JPsustainND	Annual report WP5	Midterm (2017) and final evaluation
40 A JPND Advocacy plan targeting policy makers at the EU and national levels	Annual report WP5	Midterm (2017) and final evaluation
41 Annual conferences, workshops and seminars	Annual report WP5	Midterm (2017) and final evaluation
42 Incorporate appropriate stakeholders into the JPND communications infrastructure via the Information Management Team, which will be created under JPsustainND.	Annual report WP5	Midterm (2017) and final evaluation
43 The number of unique visits to JPND website, number of followers / subscribers to JPND news feeds/social media, JPND search engine ranking	Annual report WP5	Midterm (2017) and final evaluation
44 The number of generalised and specialized media hits and press articles to raise awareness and potential extension of JPND	Annual report WP5	Midterm (2017) and final evaluation
45 Increased number of policy-making stakeholders in JPND stakeholders database	Annual report WP5	Midterm (2017) and final evaluation
46 Integration of appropriate stakeholders and stakeholder concerns into JPND communications content	Annual report WP5	Midterm (2017) and final evaluation

Table 5: Type B indicators regarding the scientific and societal impact of JPND research in the field of neurodegenerative diseases related to the objectives of JPsustainND.

Type B Performance indicators	Source (how to measure)	How often to be measured
I. Long-term sustainability		
1 The number of collaborative research projects funded through JPND joint calls that address the scientific priorities identified by JPND	Annual report WP2	Midterm (2017) and final evaluation
2 The number of non-project funded activities that address the scientific priorities identified by JPND	Annual report WP2	Midterm (2017) and final evaluation
3 Variety of actions and instruments used for the implementation plan for a collaboration platform	Annual report WP2	Midterm (2017) and final evaluation
4 The number of European-wide population-based studies with a contribution from JPND	Annual report WP2 / Bibliometric study in member countries, outsourced to service provider	Midterm (2017) and final evaluation
5 The number of scientific publications in highly ranked journals focusing on prevention, diagnosis and treatment resulting from JPND supported projects	Annual report WP2 / final reports projects supported by JPND	Midterm (2017) and final evaluation
6 Regular interaction between JPND and researchers	Annual report WP2	Midterm (2017) and final evaluation
II. Capacity extension of JPND beyond its current membership		
7 The existence of an up-to-date overview of neurodegenerative disease research programmes and initiatives	Annual report WP3	Midterm (2017) and final evaluation
8 Updated JPND Research Strategy for science and innovation	Annual report WP3	Midterm (2017) and final evaluation
9 The existence of a web portal that provides access to high level information on available cohort studies of value for neurodegenerative disease research	Annual report WP3	Midterm (2017) and final evaluation
10 Updated JPND searchable database on the scope and spread of research related to neurodegenerative diseases	Annual report WP3	Midterm (2017) and final evaluation
11 Satisfaction of researchers about accessibility and availability of information by means of web portal	Survey researchers / Baseline is the mapping exercise performed by WP3	Final evaluation
III. Alignment of national and JPND research strategies		
12 Innovative strategies to facilitate wider access to technology platforms and infrastructures such as biobanks, informatics capabilities and neuroimaging	Annual report WP4	Midterm (2017) and final evaluation
13 The number of products (e.g. guidelines, protocol standards, changes in professional practice) applied in policy and practice as a result of granted JPND supported projects	Annual report WP2 / final reports of granted JPND projects / annual report WP4	Midterm (2017) and final evaluation
14 Regular interactions between JPND and stakeholder groups (patient organisations, healthcare practitioners, industry)	Annual report WP4	Midterm (2017) and final evaluation
15 Number of interactions with relevant EU groups (ESFRI) or international networks	Annual report WP4	Midterm (2017) and final evaluation
16 Exchange of (best) practices across different types of research (basic, clinical and healthcare)	Quality analysis (to be defined)*	Midterm (2017) and final evaluation

*With regard to the Type B outcome and impacts indicators a suitable qualitative analytical method (e.g. questionnaire amongst identified stakeholder groups) should be developed in close interaction with the WP leaders. The monitoring team (WP6) would be responsible for the design and distribution of the questionnaire and the collection and analysis of data.

Annex 2: Key concepts and abbreviations

Concept	Explanation
AAL	Ambient Assisted Living
CSA	Coordination and Support Action
EB	Executive Board
EC	European Commission
ESFRI	European Strategy Forum on Research Infrastructures
EU	European Union
H2020	Horizon 2020
IMI	Innovative Medicine Initiative
JPI	Joint Programming Initiative
JPND	Joint Programming initiative on Neurodegenerative Diseases
MB	Management Board
MoU's	Memorandum of Understanding's
SRA	Strategic Research Agenda, JPND Research strategy
ToR	Terms of References