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Monitoring and evaluation of EU Joint Programming - Neurodegenerative Diseases Research (JPND)

(i) Monitoring and evaluation framework and (ii) Questionnaire 'attitudes towards JPND'



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Introduction

This document contains two aspects of the process of monitoring and evaluation of the EU Joint Programming – Neurodegenerative Diseases Research (JPND)¹: (i) the framework for monitoring and evaluation including a set of indicators of performance and (ii) a questionnaire amongst participating countries to investigate the attitude and opinions towards the initiative. The information in this document is based on an earlier version, which has been discussed during two Management Board meetings of JPND in Paris in November 2011 and in Rome in January 2012. The feedback gathered during these meetings and by mail consultation amongst the Management Board members of JPND is taken into account in order to get a document that aligns with the ideas and perceptions of the members of the Management Board, thus the focus of JPND. This document is to be used as the starting point for JPND's monitoring and evaluation process.

The first part of this document focuses on the framework of monitoring and evaluation. This framework is based on a logical framework analysis of the JPND initiative, the methodological approach that supports the development of a monitoring and evaluation framework for JPND. 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 results from interviews with members of JPND's Executive Board (EB), Steering Committee (SC) and Scientific Advisory Board (SAB) as well as the JPND Research Strategy that has recently been launched are taken into account in order to validate the initiative's intervention logic. It has to be mentioned beforehand that the monitoring and evaluation framework focuses on the level of the JPND initiative as a whole. It is therefore not intended to monitor the individual work packages of the JUMPAHEAD project, although information from the individual work packages of this EU FP7 co-ordination action is included in the framework.

The second part of this document consists of a questionnaire that will be distributed amongst all members of JPND's Management Board during Spring 2012 in order to investigate the attitudes and opinions towards the initiative from a country's and organisation's perspective. As part of the monitoring process, this exercise will be repeated close to the end of the lifetime of the JUMPAHEAD project to compare the results.

The document ends with the planning of the monitoring and evaluation process of JPND for the next two years.

Bastian Mostert,

technopolis [group], April 2012

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

1. JPND monitoring and evaluation framework

This first part presents the framework for monitoring and evaluation of JPND, based on its aim and intention (1.1), the rationale or logic of the initiative (section 1.2), the methodological approach developing this framework (1.3), a list of proposed indicators of performance that will serve as the starting point for monitoring and evaluation of the initiative (1.4) and a brief overview of the information needed for the (bi-)annual monitoring cycles and the (midterm and final) evaluation of JPND (1.5).

1.1 Aim of the monitoring and evaluation framework

In the description of JUMPAHEAD's work package 5 (framework for monitoring and evaluation of JPND) the objective of this exercise is formulated as *"to develop indicators of success and monitor the merits of the **new way of performing research** on the European level"*² (i.e. the concept of joint programming). Therefore the framework focuses above all on the process of joint programming.

1.2 Rationale or logic of JPND

The rationale for JPND has been set out in a number of key documents about the realisation and design of the initiative. These documents are:

- The 2009 European council recommendation for joint programming on neurodegenerative diseases³.
- The 2010 workplan of the JUMPAHEAD project, a EU FP7 co-ordination action supporting the implementation of the JPND initiative.
- The JPND Research Strategy⁴ that has been launched in February 2012.

The monitoring and evaluation framework is being developed in line with these documents (i.e. the included objectives, activities and intended effects and impacts of JPND) and validated by means of a number of interviews with people closely involved in JPND's management.

1.2.1 Logical Framework Analysis (LFA)

One of the most useful tools for monitoring and evaluation of a public policy programme or intervention is a logic chart or logic model. This is an analytical tool that provides a structured approach looking at the programme or intervention. It helps in all stages, from policy design to monitoring and evaluation and is therefore considered to be a highly effective approach.

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). Although we can establish logical links between activities and outputs, measuring this is extremely difficult due to attribution problems, particularly in

² Description of Work of the "Coordination Action in support of the implementation of a Joint Programming Initiative for Combating Neurodegenerative Diseases, in particular Alzheimer's disease". Project acronym: JUMPAHEAD.

³ European Commission, proposal for a council recommendation on measures to combat neurodegenerative diseases, in particular Alzheimer's, through joint programming of research activities (COM (2009) 379/3).

⁴ JPND Research Strategy, tackling the challenge of Alzheimer's and other neurodegenerative diseases in Europe.

The objective of the monitoring and evaluation framework is *"to develop indicators of success and monitor the merits of the new way of performing research on the European level"*.

complex research environments. Generic intervention logics are made up of the following steps:

1. An analysis of the (societal) challenges, needs or issues that need intervention, assuming that markets and other normal social processes are not able to correct them (i.e. the principle of subsidiarity). These societal problems are translated into rationales or reasons for policy intervention.
2. This analysis of problems and associated policy reasons implies a set of objectives, with the aim to address and ideally solve the defined (societal) problems.
3. An intervention therefore provides inputs, typically in terms of financial and other resources. In the world of research and innovation the inputs are mostly defined in terms of research funding.
4. The inputs enable activities that are expected to lead to outputs. These are the direct results of the work enabled by the inputs, which can normally be specified in a project contract.
5. The outputs enable wider results or outcomes to be created. Usually, however, in R&D and innovation funding, these outcomes primarily affect the direct beneficiaries of the funded research. In this sense, the general society has not yet received a payback on its investments.
6. The results or outcomes enable wider (economic or societal) impacts that also affect society at large.

1.2.2 The intervention logic of JPND

Figure 1 shows a schematic overview of JPND’s intervention logic: the challenges the initiative addresses (the background), the associated rationales or reasons for joint programming, its objectives and activities. Furthermore, the scheme also provides an overview of the expected outputs, outcomes and wider impacts of JPND. Each of these elements is explained below. For clarification, a distinction is made between aspects related to the process of joint programming (the upper part of the diagram) and the scientific focus and societal view of JPND (the lower part). More detailed information about the scientific focus of JPND is found in the recently published JPND Research Strategy.

Challenges for JPND

The background for the development of a joint programming initiative focusing on neurodegenerative diseases can be found in the debilitating and largely untreatable character of these disorders that are strongly linked with age. Among these disorders, dementias cause the largest burden of disease, not only on patients themselves, but also on families, caregivers and healthcare systems. Currently around 7 million European citizens are suffering from neurodegenerative diseases (especially Alzheimer’s diseases and related disorders) and as a result of the ageing population this number is expected to double every twenty years.

Furthermore, the healthcare costs for treating people with dementia all over Europe adds up to approximately €130 billion per year. Over the last decade these costs have already shown a tremendous increase, due to amongst others a growth in the number of people requiring care, rising doctor and hospital costs, the spending on drug prescription, stricter regulations and the rise of chronic diseases. Because of the demographic changes these costs are likely to increase considerably over the next decades and will affect both the cure and care side of the healthcare spectrum.

Treatments that prevent or stop the progression of neurodegeneration are still lacking. Interventions that are available only treat the symptoms and not the cause. Due to a lack of early clinical diagnoses, interventions are generally too late to have a significant impact. There is also a gap in the understanding of environmental exposure risks in early life. The underpinning scientific challenge is to improve the understanding of

A Logical Framework Analysis (LFA) starts with an overview of (societal) challenges, the associated rationales for policy intervention and the objectives of the initiative and the inputs necessary to realise them.

The activities that are performed in order to achieve the defined goals will lead to immediate outputs, longer-term results and finally wider (economic or societal) impacts.

The Research Strategy provides more detailed information about the scientific focus and societal view of JPND.

The challenges for JPND are the ageing European population, the increasing number of people suffering from neurodegenerative diseases, the rise in the costs of healthcare and the lack of clinical treatments, interventions and early diagnoses.

neurodegenerative diseases, provide new approaches for their prevention, diagnosis and treatment, and ensure effective provision of healthcare, social care and support to optimise quality of life at all stages of illness.

Rationales for joint programming

The rationales for the concept of joint programming (i.e. better coordination and harmonisation) are the level of duplication and fragmentation and compartmentalisation of research, lack of linkages between disease factors and research disciplines and the complexity of the brain system.

Tackling these challenges lies clearly beyond the scope and resources of any one country. In JPND, 24 European countries have established an innovative collaborative research initiative, aligning national programmes to increase the impact and effectiveness. The challenges thus require a more coordinated and harmonised approach in terms of research efforts.

There is a considerable level of duplication and fragmentation in research activities related to neurodegenerative diseases throughout the different European countries. The reduction of unnecessary duplication and fragmentation within a European context is needed.

Another rationale for joint programming is to promote a more holistic, multifactoral and multidisciplinary research approach. The research activities are too often highly compartmentalised, without sufficient interaction between different disease factors and research disciplines. In case of research in the neurodegenerative diseases domain, necessary linkages between basic, clinical and healthcare research (the different types of research) need to be strengthened.

Furthermore, the complexity of the brain and associated systems of the human body ask for a longer-term focus for research. The strength of a longitudinal approach using large cohort and population studies has contributed significantly to the understanding of risk factors associated with neurodegenerative diseases. Integrating population data with genetic, cellular, and imaging data will eventually accelerate the translation of research findings into effective clinical interventions.

Objectives

Based on the challenges and rationales for joint programming in the field of neurodegenerative diseases, a number of objectives are articulated for JPND. A distinction is made between objectives related to the process of joint programming (i.e. the policy level) and those related to specific scientific and societal issues that JPND addresses.

The objectives of the process of the concept of joint programming are the identification of common goals for joint actions, the creation of new and extension of national research programmes and the creation of critical mass.

The objectives of the act of joint programming (the so-called policy objectives) are the identification of common goals that would benefit from joint actions. This comprises the establishment and alignment of national research programmes dedicated to neurodegenerative diseases, the creation of critical mass of research capacity in this domain across Europe (in particular for clinicians and translational scientists) and the development of a framework for an integrated approach in basic, clinical and healthcare research. JPND furthermore encourages the implementation of experiences into evidence-based policies and best practices.

The scientific and societal objectives align with the priorities of the Research Strategy: increase of the understanding of NDD (the establishment of population studies, the development of models), the development of diagnostic criteria, biomarkers, treatments and preventive strategies.

The scientific and societal objectives (priorities) of JPND are mentioned explicitly in the JPND Research Strategy⁵ that was developed in the first phase of the joint programming process. In the JPND research Strategy four main themes are identified: (1) understanding disease; (2) disease progression; (3) interventions and (4) society and policy. Understanding the disease is about understanding the origins and mechanisms (by means of the establishment of European-wide population-based and longitudinal studies and the development of animal and cell-based models), while pathology and diagnosis are important elements of understanding the disease

⁵ JPND Research Strategy, tackling the challenge of Alzheimer's and other neurodegenerative diseases in Europe.

progression by means of the development (not in clinical practice) of new diagnostic criteria, biomarkers and treatments. Interventions are targeted towards preventive strategies, treatment and care/management. The promotion of research in non-specialist settings (e.g. primary and community care) is an important objective within the society and policy theme. Further objectives are the stimulation of education and training of healthcare professionals, the improvement of public health education and destigmatisation of patients suffering from neurodegenerative diseases. Furthermore, these objectives touch upon the engagement of lay participants (patients, caregivers and families) in research and raising the awareness of the importance and necessity of research on neurodegenerative diseases.

Activities

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 the process of joint programming (the policy level), JPND will perform the coordination of different tasks. Other activities focusing on the policy level are the exchange of information on national programmes, research activities and healthcare systems (i.e. the mapping exercise of the research activities in the domain of neurodegeneration that is conducted in 2011). The major activity to address the policy objectives was the development of a research strategy in the domain of neurodegenerative diseases, which has recently resulted in its publication⁶ and launch in February 2012. Another activity is the coordination of joint calls for proposals and other non-project related activities.

On the scientific and societal level the implementation (delivery) of the research strategy is the main activity of JPND. The strategy will be implemented either through carrying out co-operative activities (such as data sharing for instance) that realign or link national investments or through the provision of new funding. Other activities related to the scientific objectives of JPND are the research activities performed through joint calls for proposals. The joint calls for proposal that have been published until now focused at the collaboration between existing centres of excellence on neurodegeneration and the harmonisation of biomarkers. Other activities on the societal level are the communication about JPND and dissemination of its progress to relevant stakeholders and the facilitation of transdisciplinary and cross-sectoral mobility and training of researchers.

Outputs

From the proposed activities and the JPND Research Strategy a set of direct outputs is to be expected that can be directly linked to JPND's efforts.

On the level of the process of joint programming there will be an increase in the number of researchers active in the domain and better collaboration between them (clustering of knowledge), between the national funding agencies responsible for national research funding (clustering of funding calls) and between existing centres of excellence on the use and sharing of research infrastructures.

On the scientific and societal level there will be an expansion of current research activities in the domain of neurodegenerative diseases by individual countries because of the development of either formal or informal national research strategies based on the JPND Research Strategy. These research activities will be more focused at prevention, diagnosis and treatment of neurodegenerative diseases. The choice for research topics will be better aligned between individual countries. Furthermore,

Other objectives are the stimulation of education and training of healthcare professionals, the destigmatisation of patients and raising the awareness of the importance of research on neurodegenerative diseases.

The coordination task of JPND is the most important activity on the policy level (exchange of information on national programmes, the development of the Research Strategy, joint calls for proposals and other non-project related activities).

The activities focused on the scientific and societal level of JPND are the implementation (delivery) of the Research Strategy, research performed through joint calls for proposals and dissemination and facilitating transdisciplinary and cross-sectors mobility and training.

The outputs related to the process of joint programming are an increase in the number of researchers and better collaboration in research (funding).

The scientific and societal outputs are an expansion of research activities focused at prevention, diagnosis and treatment, the establishment of population-based studies and patient cohorts and information about the current state of research.

⁶ JPND Research Strategy, tackling the challenge of Alzheimer's and other neurodegenerative diseases in Europe.

JPND will contribute to the execution of European-wide population-based studies and the establishment of patient cohorts and information about the current state of neurodegenerative diseases research.

Outcomes

On a level of the process of joint programming there will be an increase in strategic cooperation among EU Member States and with third countries in neurodegenerative diseases domain combined with an increase in the amount of research funding available for neurodegenerative diseases research compared to the situation before JPND. Also there will be a reduction in the amount of duplication and fragmentation of research activities.

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 new diagnostics, preventive strategies and therapies in clinical pipeline and the reduction of the number of stigmatised patients.

Impacts

The wider impacts that are ideally to be expected to occur are also included in the JPND Research Strategy but can be captured in the following aspects. JPND will be able to be considered to be model for future research collaboration in Europe (and beyond). It will also achieve an increase of the capacity in neurodegenerative diseases research and associated investments in European research for these diseases.

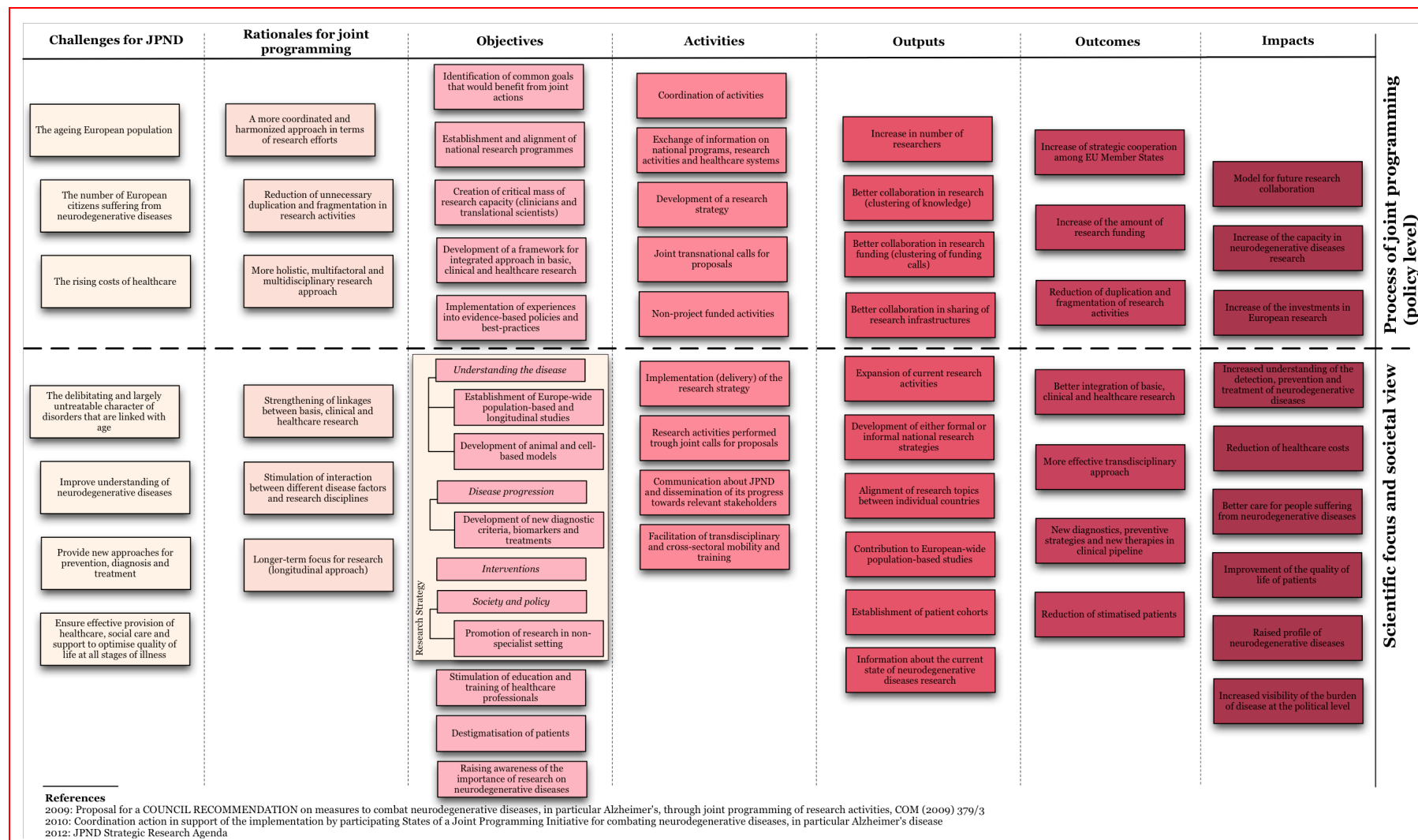
On the scientific and societal level there will be an increased understanding on the detection, prevention and treatment of neurodegenerative diseases resulting in lower costs of healthcare, better care for people suffering from these diseases and finally an improved quality of life of patients. Furthermore impact is to be expected on the raised profile of neurodegenerative diseases and an increased visibility of the burden of these diseases at the political level.

It has to be mentioned again that the outcomes and impacts that are defined above are not to be expected to occur during the lifetime of the JUMPAHEAD project (i.e. the before the end of 2013). Therefore these aspects will not be integrated in the monitoring cycles. In the final evaluation of JPND, which should take place in a couple of years (preferably five), the longer-term outcomes and impacts can be assessed in more detail.

The longer-term outcomes of JPND are considered to be an increased cooperation between countries, better integration of basic, clinical and healthcare research, new diagnostics, preventive strategies and therapies, and less stigmatised patients.

The wider impacts are the fact that JPND will be seen as model for future research collaboration, an increased research capacity with associated investments and better understanding of detecting, preventing and treating neurodegenerative diseases.

Figure 1 Intervention logic of JPND



Process of joint programming (policy level)

Scientific focus and societal view

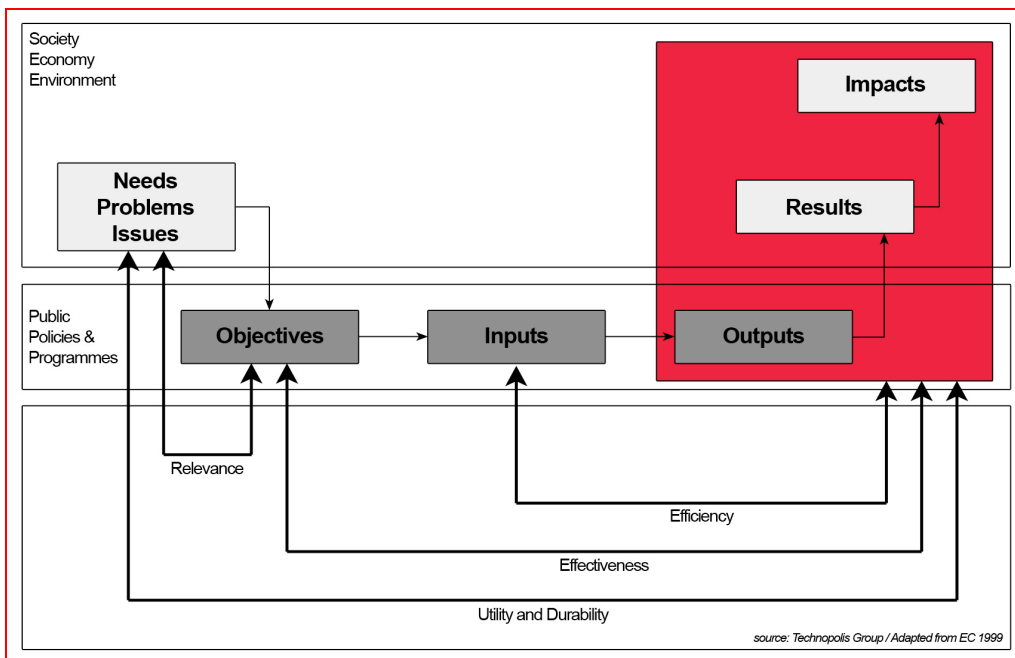
Source: Technopolis Group analysis, based on JPND documentation (2012).

1.3 Monitoring and evaluation framework

The set of indicators of performance will be used to fit in a general evaluation framework that is considered as ‘good practice’ in science and technology programme monitoring and evaluation. Below a simplified model of this evaluation framework is presented. In general, monitoring and evaluation is concerned with the following issues:

- **Relevance:** the issue of relevance consists of examining whether the objectives of a policy intervention correspond with the (societal) challenges, problems and issues at the level of its critical clients and beyond.
- **Effectiveness:** the issue of effectiveness is especially pertinent in the context of a midterm and ex-post evaluation. It consists of the question whether the results and impacts generated by the supported activities correspond with the objectives.
- **Efficiency:** the issue of efficiency consists of examining the level of resource use (inputs) required to produce outputs and generate effects. In other words, optimisation of resource utilisation is concerned. An activity that is assessed as having an effect may not necessarily be efficient: the same effect could have been reached with less resources.
- **Utility:** the issue of utility consists of looking for expected and unexpected effects (i.e. those that were not identified as objectives during the design phase) and whether these, when they are positive, correspond with (societal) challenges, problems and issues of different groups in society and economy.
- **Sustainability:** the issue of sustainability consists of examining whether the positive impacts on critical clients and beyond would continue in the future, even after the ending of an activity.

Figure 2 Evaluation framework



Source: Technopolis Group.

1.4 Indicators for measuring JPND's success

This document sketches the proposed framework for monitoring and evaluating the merits of the new way of performing research on the European level (i.e. the concept of joint programming). It addresses different indicators of performance, including those that can be used for (bi-)annual monitoring exercises of JPND, and those that are specifically suited for its (midterm and final) evaluation.

1.4.1 Deriving indicators of performance

When a public policy initiative is designed, it is important to set the indicators or measures that will be used to guide it, ensure that necessary corrective actions are taken if things do not go according to plan and assumptions, and identify the effects it has produced. One useful way of thinking about indicators is 'what signs or changes will tell us that we have achieved our objectives?'

Indicators are often quantitative – you can count or measure them. They can be based on facts (e.g. number of scientific articles that are published) or opinions (e.g. % of member states is satisfied with the achievements of JPND). If a proper intervention logic is developed, indicators should be easy to construct, as each box in the intervention logic holds a potential measure. Indicators are used to measure or demonstrate change or progress: it is therefore important to not only know where you are heading for (the target/objective) and where you are compared to that, but also where you started from (the baseline).

The set of indicators used does not necessarily remain static during the lifetime of the initiative. Monitoring or evaluation may reveal the need for adjustment in the 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.

1.4.2 Types of indicators for 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 have been established 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 in clinical pipeline 3 years after the start, or increased collaboration in research and research funding).
- **Impact indicators** measure the long-term socio-economic changes the intervention brings about (e.g. the increase in quality of life for people suffering from neurodegenerative diseases).

Although a couple of outcome and impact indicators are defined, in the context of monitoring the progress of JPND the focus will be on the first two: the input and outputs indicators. This because outcomes and impacts need some time to occur (i.e. they are not to be expected within a period of three years) and are sometimes hard to attribute to the initiative. These longer-term effects are only taken into account in the final evaluation of the initiative, not in the monitoring cycles during the lifetime of the JUMPAHEAD project.

For JPND in particular two types of indicators have been identified following JPND’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.

A useful tool for designing the indicators is the table shown in Figure 3. This ensures that the defined indicators measure those aspects that they are intended to, that external factors are identified so the strength or weakness of the indicator can be assessed, and the source and method of collection of the data is recorded. Using this framework, a judgement can be made on the indicators that can be collected and how they will be used.

Figure 3 Indicator analysis framework

Intended input/output/outcome/impact	Success criteria	Indicator	Source of data
What is the stated objective?	How will you know when it has been achieved?	What measure will you use?	Where will you get the data from and how will you or somebody else collect it?
↑	↑	↑	↑
<i>From the LFA and Research Strategy</i>	<i>What (realistic) targets have you set? (from Research Strategy)?</i>	<i>Have you a clearly defined indicator (RACER)?</i>	<i>What will be the resources and cost of collecting the indicator?</i>

The tables on the next few pages contain the list of indicators to be used for the monitoring and evaluation of JPND. A distinction is made between type A and type B indicators and the different indicator categories (input, output, outcome and impact). Some of the aspects of expectations are spelled out in more detail in the questionnaire to investigate attitudes towards JPND (see Chapter 2).

1.4.3 Overview of indicators of performance

The next table provides the proposed list of indicators, which will be further specified in the tables on the next couple of pages. Please note that only the input and output indicators are taken into account in the monitoring cycles of JPND. The outcome and impact indicators will only be measured in the final evaluation of the initiative.

Figure 4 Overview of all proposed indicators of performance

Indicator category	Type A	Type B
Input	<ul style="list-style-type: none"> • Participation grade of Member States in Management Board meetings (a.1). • Attitude towards JPND goals and objectives (a.2). • Opinion on the progress and anticipated results of JPND (a.3). • The drop out of countries (a.4). • Participation grade of Member States in JPND Research Strategy implementation working groups (a.5). • The number of new joint transnational calls for proposals (a.6). • The share of granted projects versus the number of applications (a.7). • The number of new initiatives for non-project funded activities (a.8). 	<ul style="list-style-type: none"> • The number of collaborative research projects funded through JPND joint calls that address the various scientific priorities (b.1). • The number of non-project funded activities that address the various scientific priorities (b.2).
Output	<ul style="list-style-type: none"> • The national research (funding) priorities adapted as result of JPND and the (scientific) priorities of JPND's Research Strategy (a.9). • Alignment of national research funding programmes (a.10). • New or updated country strategies that mirror the impact of JPND (a.11). • Efficiency benefits through pooling (a.12). • Allocated funding through joint transnational calls for proposals or non-project funded activities (a.13). 	<ul style="list-style-type: none"> • The existence of an up-to-date overview of neuro-degenerative diseases research programmes and initiatives (b.3). • The number of Europe-wide population-based studies with contribution of JPND (b.4). • The number of large-scale longitudinal and cross-sectional population cohorts initiated since the start of JPND (b.5). • Satisfaction of researchers about accessibility and availability of information by means of databases (b.6). • The number of databases that is widely accessible for researchers in the domain of neurodegenerative diseases (b.7).
<i>Not included in monitoring cycles of JPND during lifetime of the JUMPAHEAD project</i>		
Outcome	<ul style="list-style-type: none"> • The amount of JPND common research funding for neurodegenerative diseases as share of total EU research funding (a.14). • The total amount of European funding available for neurodegenerative diseases research (a.15). 	<ul style="list-style-type: none"> • The number of scientific publications in high ranked journals focusing on prevention, diagnosis and treatment over the years as a result of granted JPND projects (b.8). • Regular interactions between JPND and stakeholder groups (b.9).
Impact	<ul style="list-style-type: none"> • The number of publications in high impact journals of European researchers as share of world in neurodegenerative diseases research (a.16). • Investment in European R&D in neurodegenerative diseases research as share of total investment in R&D (a.17). 	<ul style="list-style-type: none"> • Public opinion of neurodegenerative diseases (b.10). • Exchange of practices across different types of research (basic, clinical and healthcare) (b.11). • Quality of life judgement by patients and caregivers in existing studies (b.12).

1.4.3.1 Type A indicators

The following tables present the indicators that focus on the effect of JPND on (European) research programming, research policy and funding (the type A indicators).

Figure 5 Type A input indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Strong commitment of participating countries to JPND	80% of the participating countries (by means of their representatives) attend the Management Board meetings per year.	Participation grade of Member States in Management Board meetings (a.1).	The percentage of the total number of Management Board meetings per year attended by JPND Member States (only the official meetings are being counted).	Minutes of Management Board meetings	Monitoring team (WP5), based on information provided by the secretariat (WP1)	Semi-annual (each monitoring cycle)
Expectations by JPND countries reached	90% of the participating countries (representatives) is satisfied with the goals and objectives of JPND as mentioned in the Logical Framework Analysis or the JPND Research Strategy	Attitude towards JPND goals and objectives (a.2).	The number of Member States representatives that is satisfied by the drafted objectives and goals mentioned in the Logical Framework (based on the Research Strategy) and discussed during the meetings (by means of a 5 points 'Likert'-scale).	Questionnaire amongst Member States representatives (see chapter 2)	Monitoring team (WP5)	Twice: (1) mid-2012 and (2) at the end of 2013
	The majority of the participating countries (representatives) have high expectations of the achievements of JPND.	Opinion on the progress and anticipated results of JPND (a.3).	See various questions in the questionnaire (i.e. 17, 18 and 19) (by means of a 5 points 'Likert'-scale).	Questionnaire amongst Member States representatives (see chapter 2)	Monitoring team (WP5)	Twice: (1) mid-2012 and (2) at the end of 2013
No country opts out of JPND	All participating countries continue in JPND.	The drop out of countries (a.4).	Opt out of participating countries means both no longer formal or informal participation in JPND. Informally contains those countries that do not attend meetings anymore or countries that do not provide any funding.	Minutes of Management Board meetings	Monitoring team (WP5), based on information provided by the secretariat (WP1)	Semi-annual (each monitoring cycle), midterm evaluation and final evaluation

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Implementation of JPND's Research Strategy	80% of the participating countries (representatives) take part in one of the JPND's Research Strategy implementation working groups.	Participation grade of Member States in JPND's Research Strategy implementation working groups (a.5).	The percentage of Member States participating in JPND's Research Strategy working group meetings (only official meetings are being counted).	Minutes of working group meetings	Monitoring team (WP5), based on information provided by the working group chairs	Semi-annual (each monitoring cycle)
Joint transnational calls for proposals	The launch of at least 2 joint transnational calls for proposals after 3 years that contribute to the implementation of the JPND Research Strategy.	The number of new joint transnational calls for proposals (a.6).	The number of joint transnational calls for proposal published and the number of granted projects.	Annual report of WP3	Monitoring team (WP5), based on information provided by WP3	Semi-annual (each monitoring cycle)
	60% of the applications in joint transnational calls for proposals are granted.	The share of granted projects versus the number of applications (a.7).	The percentage of granted projects related to the total number of applications.	Annual report of WP3	Monitoring team (WP5), based on information provided by WP3	Semi-annual (each monitoring cycle)
Initiatives for non-project funded activities	The launch of at least 2 collaborative initiatives for activities after 3 years that contribute to the implementation of the JPND Research Strategy.	The number of new initiatives for non-project funded activities (a.8).	The number of new initiatives for non-project funded activities initiated in which more than two countries participate	Annual report of WP3, Minutes of (Management Board) meetings	Monitoring team (WP5),	Semi-annual (each monitoring cycle)

Figure 6 Type A output indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Increased coordinated and harmonised research funding	JPND has influenced the national focus of neurodegenerative diseases research policies and instruments.	The national research (funding) priorities adapted as result of JPND and the (scientific) priorities of JPND's Research Strategy (a.9).	Qualitative statement on influence of JPND (and its Research Strategy) by funders and policymakers.	Questionnaire amongst Member States representatives (see chapter 2)	Monitoring team (WP5)	Twice: (1) mid-2012 and (2) at the end of 2013

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Increased coordinated and harmonised research funding <i>(continued)</i>	The participating countries have managed to align their national programmes due to JPND.	Alignment of national research funding programmes (a.10).	The contents of research funding programmes is adapted based on the scientific priorities as defined in JPND's Research Strategy to be complementary to/match with programmes in other countries.	Questionnaire amongst Member States representatives (see chapter 2)	Monitoring team (WP5)	Twice: (1) mid-2012 and (2) at the end of 2013
	The development of new or updated strategies that mirror the impact of JPND.	New or updated country strategies that mirror the impact of JPND (a.11).	Those member states that not already have a national strategy develop one and those that already have one should update its strategy aligned with the scientific priorities as defined in JPND's Research Strategy.	Questionnaire amongst Member States representatives (see chapter 2)	Monitoring team (WP5)	Twice: (1) mid-2012 and (2) at the end of 2013
	The benefits of the international calls for proposals and non-project funded activities outweigh the transaction and administrative costs of JPND.	Efficiency benefits through pooling (a.12).	The total costs for preparing JPND bids (mostly working hours spent on preparation, selection and contracting) are measured in relation to the size of the research budget, costs of non-project funded activities (total costs).	At early stage: qualitative statement Questionnaire amongst Member States representatives (see chapter 2)	Monitoring team (WP5), partly based on information provided by WP3	Semi-annual (each monitoring cycle) Twice: (1) mid-2012 and (2) at the end of 2013
	The funding allocated annually via joint calls for proposals or non-project activities within JPND increases to 5% of total coordinated funding available (EU Framework Programmes and Joint Programming together) and the total budget should increase 10% after 4 year.	Allocated funding through joint transnational calls for proposals or non-project funded activities (a.13).	The amount of EU Framework Programme and Joint Programming funding on neurodegenerative diseases: at the start of JPND: FP funding = 100% JP funding = 0%. The amount funded in € to the awarded projects in the calls or non-project funded activities in the year of start for the whole time period of the project.	Annual report of WP3	Monitoring team (WP5), based on information provided by WP3	Semi-annual (each monitoring cycle)

The two tables below present the proposed outcome and impact indicators. As mentioned before, these indicators are left outside the scope of the monitoring cycles of JPND (i.e. during the lifetime of the JUMPAHEAD project). These indicators are only used in a final evaluation of JPND, preferably after a period of five years from the start of the initiative.

Figure 7 Type A outcome indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Reduction of the fragmentation of research activities in the domain of neurodegenerative diseases	Because of the efforts of JPND, the share of funding for neurodegenerative diseases research by JPND has reached 5% of total European research funding in this domain.	The amount of JPND common research funding for neurodegenerative diseases as share of total EU research funding (a.14).	The funding in neurodegenerative diseases areas commissioned jointly as a proportion of the aggregated national research funding including that of the European Commission & European Research Council.	Repetition of the mapping exercise Questionnaire amongst Member States representatives (see chapter 2)	National authorities involved in joint programming. Baseline is the results of the mapping exercise performed by WP2.	Final evaluation
Increase of the amount of research funding	Because of the efforts of JPND, the total amount of research funding available for neurodegenerative diseases has increased since the start of JPND	The total amount of European funding available for neurodegenerative diseases research (a.15).	The total amount of European funding available for neurodegenerative diseases research.	Repetition of the mapping exercise Questionnaire amongst Member States representatives (see chapter 2)	National authorities involved in joint programming. Baseline is the results of the mapping exercise performed by WP2.	Final evaluation

Figure 8 Type A impact indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Increased capacity in neurodegenerative diseases research	European researchers are world leading in neurodegenerative diseases research: increase in the number of publications in high impact journals.	The number of publications in high impact journals of European researchers as share of world in neurodegenerative diseases research (a.16).	The evolution of the number of scientific publications in high impact journals by European researchers in the domain of neurodegenerative diseases research (aligned with the scientific priorities as defined in JPND's Research Strategy.	Bibliometric study	Management Board, outsourced to service provider.	Final evaluation

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Increased attention by public and private parties for neurodegenerative diseases R&D	Increased investment in European R&D in neurodegenerative diseases domain.	Investment in European R&D in neurodegenerative diseases research as share of total investment in R&D (a.17).	The total European investments in R&D in the domain of neurodegenerative diseases research.	Repetition of mapping exercise, desk study	National authorities involved in joint programming. Baseline is the results of the mapping exercise performed by WP2.	Final evaluation

1.4.3.2 Type B indicators

The following tables present the indicators regarding the scientific and societal impact of JPND research on the domain of neurodegenerative diseases (the type B indicators).

Figure 9 Type B input indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
High quality of funded cross-border research projects started through JPND	At least 4 projects are launched annually with a total budgetary weight of at least €10 million.	The number of collaborative research projects funded through JPND joint calls that address the various scientific priorities (b.1).	The number of granted collaborative projects through the joint calls for proposals addressing the scientific priorities as defined in JPND's Research Strategy.	Annual report of WP3	Monitoring team (WP5), based on information provided by WP3	Semi-annual (each monitoring cycle)
Cross-border initiatives started through JPND	At least 3 initiatives (non-project funded) are launched annually.	The number of non-project funded activities that address the various scientific priorities (b.2).	The number of collaborative initiatives that are initiated addressing the scientific priorities as defined in JPND's Research Strategy.	Annual report of WP3	Monitoring team (WP5), based on information provided by WP3	Semi-annual (each monitoring cycle)

Figure 10 Type B output indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Mapping of research programmes in the neurodegenerative diseases domain in Europe	An updated map of research programmes available in an open access database	The existence of an up-to-date overview of neurodegenerative diseases research programmes and initiatives (b.3).	A research programme is a well-established research plan with various actions, led by a programme manager and encompasses support from a number of senior researchers.	Repetition of the mapping exercise	National authorities involved in joint programming. Baseline is the results of the mapping exercise performed by WP2.	Bi-annually
Contribution to Europe-wide population-based studies	JPND contributed successfully to the establishment of Europe-wide population-based studies.	The number of Europe-wide population-based studies with contribution of JPND (b.4).	The number of population-based studies all over Europe that received any sort of contribution from JPND.	Desk study	Monitoring team (WP5)	Semi-annual (each monitoring cycle)

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Large-scale population cohorts	An increase of longitudinal and cross-sectional population cohorts in the neurodegenerative diseases domain since the start of JPND.	The number of large-scale longitudinal and cross-sectional population cohorts initiated since the start of JPND (b.5).	The number of (potentially transnational) patient cohorts with large numbers of participants, large disease relevance.	Repetition of the mapping exercise, desk study	National authorities involved in joint programming. Baseline is the results of the mapping exercise performed by WP2.	Midterm and final evaluation
Large coordinated databases that could be used for population studies	Increased access to information, data sources, samples and patient cohorts for researchers in the domain of neurodegenerative diseases.	Satisfaction of researchers about accessibility and availability of information by means of databases (b.6).	Databases containing highly specific information for researchers active in the domain of neurodegenerative diseases and the degree of satisfaction on the information that is incorporated.	Investigation amongst researchers at JPND member institutes	Monitoring team (WP5)	Midterm and final evaluation
		The number of databases that is widely accessible for researchers in the domain of neurodegenerative diseases (b.7).		Repetition of the mapping exercise, desk study	National authorities involved in joint programming. Baseline is the results of the mapping exercise performed by WP2.	Midterm and final evaluation

As mentioned in the overview of type A indicators, the outcome and impact indicators of type B are also left outside the scope of the monitoring cycles of JPND (i.e. during the lifetime of the JUMPAHEAD project). The indicators in the following two tables are only used in a final evaluation of JPND, preferably after a period of five years from the start of the initiative.

Figure 11 Type B outcome indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Focussed research efforts addressing prevention, diagnosis and treatment	An increase in the number of JPND publications in the neurodegenerative diseases domain since the start.	The number of scientific publications in high ranked journals focusing on prevention, diagnosis and treatment over the years as a result of granted JPND projects (b.8).	JPND’s Research Strategy by means of its scientific priorities defines the domain of neurodegenerative diseases. Possible subjects to look at are publications about new biomarkers, new imaging techniques, new preventive strategies, new early diagnostics, etc.	Annual report of WP3 Bibliometric study in member countries	Monitoring team (WP5), based on information provided by WP3 Management Board, outsourced to service provider	Final evaluation
Engagement with identified stakeholder groups	At least two engagements with identified stakeholder groups in the domain of neurodegenerative diseases per year (patient organisations, healthcare practitioners, industry, etc.)	Regular interactions between JPND and stakeholder groups (b.9).	The stakeholder groups have been identified according to the JPND Communications Plan (e.g. patient organisations, healthcare practitioners, industry, etc.).	Regular updates from WP4	Monitoring team (WP5), based on information provided by WP4	Final evaluation

Figure 12 Type B impact indicators

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
Raised profile of neurodegenerative diseases	Neurodegenerative diseases are high on the agenda for policy makers.	Public opinion of neurodegenerative diseases (b.10).	Raised attention to neurodegenerative disease on a political level and research funding level in the participating countries of JPND.	Qualitative analysis (to be defined)	Monitoring team (WP5), based on stakeholder contact information provided by WP4	Final evaluation

Intention	Success criteria	Indicator	Definition	How to measure?	Who is responsible for data collection?	How often to be measured?
More effective care across both the medical and social domains and better care for people suffering from degenerative diseases.	Exchange of good practices, training, etc.	Exchange of practices across different types of research (basic, clinical and healthcare) (b.11).	Different types of research (basic, clinical and healthcare research) will be more integrated with each other.	Qualitative analysis (to be defined)	Monitoring team (WP5), based on stakeholder contact information provided by WP4	Final evaluation
Improve quality of life for patients, family and caregivers.	Increased quality of life for patients and caregivers as judged by majority of publications about the topic	Quality of life judgement by patients and caregivers in existing studies (b.12).	The quality of life judgement will be based on a qualitative analysis.	Longitudinal study outcomes available about QoL for people suffering from neurodegenerative diseases	Management Board	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 WP4. The monitoring team (WP5) would be responsible for the design and distribution of the questionnaire and the collection and analysis of data. For an effective measurement of public opinion of neurodegenerative diseases additional resources will be required.

1.5 What information is needed

For the collection of information with regard to 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 mapping exercise (WP2).
- Information on the granted projects in the joint call for proposals and the annual reports of the granted projects (joint call secretariat, WP3).
- Information on the outreach and communication activities (e.g. the JPND Communication Plan) (WP4).
- The questionnaire amongst Member States representatives (monitoring team, WP5) (see Chapter 2).

2. Questionnaire ‘attitudes towards JPND’

This questionnaire will be distributed mid-2012 (i.e. the beginning of May) 2012 amongst all 24 participating member states of JPND to investigate their current attitude towards the JPND initiative.

This investigation will be repeated close to the end of the JUMPAHEAD project (at the end of 2013) in order to appraise the (perceived) effectiveness and usefulness of JPND. The phrasing of the questions in the 2013 questionnaire will be adapted to focus on achieved results rather than expectations, which is the focus of the 2012 questionnaire.

This questionnaire focuses on the expectations, motivations and foreseen effects of JPND both within the own organisation and within the national research-funding context. It also contains questions focusing on the current functioning of JPND. The questionnaire will address 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 is 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

For each country, the Management Board representatives will be contacted by means of an online questionnaire, utilising a professional survey facility⁷, which is regularly used for surveys conducted at 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. Each targeted respondent is assigned a unique link to the questionnaire, which is then used to track their status (i.e. whether they have just visited or completed the survey either partially or entirely) and allows them to partly complete the questionnaire, and then return later to the exact point they were at previously. All responses (partial and complete) are logged automatically, but can be updated or amended by respondents at any point during the period in which the survey is ‘live’. We propose the questionnaire to be accessible for about a month. Reminder messages for non-respondents will be generated and sent automatically after two weeks and in case of a low response rate again close to the end of the survey cycle. Those who do not wish to respond will be able alert us by clicking a dedicated button. They won’t be contacted again with survey requests.

We suggest the information to be identifiable to a Management Board representative (i.e. the country he or she represent), instead of collecting the results anonymously. This choice is made because it will be able to track how expectations and final opinions have evolved for specific members/countries.

⁷ <http://www.surveymonkey.com/>.

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 the way the responses are collected and analysed (based on the result of the choice mentioned before) and the time frame for the collection of the responses (beginning of May till mid-June 2012).

2.1 General information

Please provide us with information that characterises you, the country and organisation you represent in the Management Board of JPND. This information will be used to categorise the answers to this questionnaire as much as possible.

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 are you personally 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. In case you just joined (i.e. you joined less than 4 months ago) the Management Board 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 group that were set up to implement JPND's Research Strategy? [No, Yes with drop down menu containing the working groups]
8. Is your organisation also actively involved in any of the following (funding) initiatives?

- ERA-NETs or ERA-NETs +
 - o FP6 - NEURON (Network on European Funding for Neuroscience Research)
 - o FP7 - ERA-instruments (Infrastructure Funding in the life sciences)
 - o FP7 - EUROCOURSE (Europe against Cancer: Optimisation of the Use of Registries for Scientific Excellence in research)
 - o FP7 - EuroNanoMed (European network of trans-national collaborative RTD projects in the field of NANOMEDicine)
 - o FP7 - EUROTRANSBIO (European programme for TRANS-national R&D&I cooperations of BIOTECH SMEs)
 - o EraNETplus - ERASysBio+ (The consolidation of systems biology research - stimulating the widespread adoption of systems approaches in biomedicine, biotechnology, and agri-food)
 - o EraNetplus - NanoSci-E+ (Transnational call for collaborative proposals in basic nanoscience research)
 - o FP6 - PathoGenoMics (Trans-European cooperation and coordination of genome sequencing and functional genomics of human-pathogenic microorganisms) (for discussion)
 - o FP7 - ERA-ENVHEALTH (Coordination of national environment and health research programmes - Environment and Health ERA-NET) (for discussion)
 - o Other... (please specify)
- European Innovation Partnership on Active and Healthy Ageing
- Joint Actions
- Innovative Medicines Initiative (IMI)
- Ambient Assisted Living Joint Programme (AAL JP)

2.2 Expectations for taking part in JPND

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

9. 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...
 - o ...with the aim of thematically focusing our own research (funding) activities.
 - o ...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 so that we 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)
10. 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.
11. 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]
12. In case your organisation actively participates in any other European initiatives like 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]

2.3 Opinions on current JPND activities

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

13. 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 process of the definition of JPND's Research Strategy was satisfactory.

- 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).
14. How do you perceive the quality of the JPND pilot call on the following aspects compared to other EC programmes (Framework Programme, etc.)? [Extremely Poor – Below Average – Average – Above Average – Excellent – Do Not Know]
- The selection process
 - The success rate
 - The administrative burden
 - The ability to attract high quality researchers
15. 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]
16. Do the additional transaction costs of JPND outweigh the foreseen benefits? [Strongly Agree – Agree – Undecided – Disagree – Strongly Disagree]

2.4 Expectations for the future

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

17. Please rank the outputs that are in your opinion are most likely to occur within the first three years of JPND (i.e. the lifetime of the JUMPAHEAD project) (1 = most likely to occur, 10 = less likely to occur).
- Increase in the number of researchers.
 - Grouping of knowledge (more collaboration between researchers in the domain 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)...

18. What do you consider the most important longer-term effects of JPND? Please indicate your top-3.

- An increase of strategic cooperation among EU Member States
- An increase of the amount of research funding in the domain of neurodegenerative diseases
- A reduction of duplication and fragmentation of research activities
- A better integration of basic, clinical and healthcare research
- More effective transdisciplinary approach
- New diagnostics, preventive strategies and therapies in clinical pipeline
- Reduction of stigmatised patients
- Other... (please specify)

19. What are in your opinion the (socio-economic) impacts that JPND is likely to effectuate (or at least contribute to)?

- JPND will be considered to be a model for future research collaboration
- An increase of the capacity in neurodegenerative diseases research
- An increase of the investments in European research in the domain of neurodegenerative diseases
- An increased understanding of the detection, prevention and treatment of neurodegenerative diseases
- A reduction of the healthcare costs
- Better care for people suffering from neurodegenerative diseases
- Improvement of the quality of life of patients
- Raised profile of neurodegenerative diseases
- Increased visibility of the burden of disease at the political level

20. Where do you expect 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 small 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 of 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)

21. 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
 - Other... (please specify)

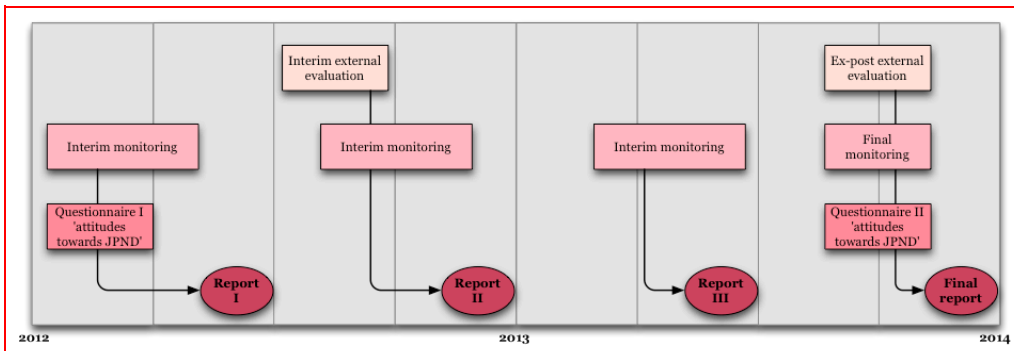
2.5 Concluding remarks

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

3. Planning of the monitoring and evaluation process

The figure below gives an overview of the planning of the monitoring and evaluation process for the next two years (i.e. the lifetime of the JUMPAHEAD project). Within this period, a total of three interim monitoring cycles are foreseen, each with a separate monitoring report. The second monitoring report will be combined with a report of the interim external evaluation that will take place mid 2012. At the end of 2013, a final monitoring will be executed together with the final external evaluation. The questionnaire to investigate the attitudes towards JPND will be distributed during the second Quarter of 2012 and will be repeated at the end of 2013.

Figure 13 Planning of the monitoring and evaluation process



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