JPND
research
EU Joint Programme – Neurodegenerative Disease Research

JPND Research and Innovation Strategy 2018: Stakeholder Consultation:

Page 1: Start Page

Online consultation on JPND's *Research and Innovation Strategy 2018* to tackle the challenge of neurodegenerative disease.

Objective:

JPND has identified through its Scientific Advisory Board common research goals that would benefit from joint action between countries to accelerate progress on solutions that can alleviate the symptoms, and lessen the social and economic impact of neurodegenerative disease (ND) for patients, families and health care systems. The aim of this public consultation is to gather views and opinions relating to a recent update to these priorities, since the release of JPND's original Strategic Research Agenda (SRA) in 2012.

Below is a short overview video on the consultation and the Research and Innovation Strategy.

This online consultation comprises of 14 pages of questions, including the entry of personal contact details. Most users will complete the consultation in around 20 minutes. Please note, questions on specific themes are optional and may not be relevant to all stakeholders groups.

Target Groups:

We welcome views and contributions from researchers, clinicians, politicians, decision makers, patients, carers and members of the public, together with administrations, associations and other organisations with an interest in neurodegenerative disease.

Period of Consultation:

17th September 2018 -8th October 2018

Short Introduction to Neurodegenerative Disease

Neurodegenerative disease is an umbrella term for a range of conditions, that include Alzheimer's disease and Parkinson's disease, which primarily affect the neurons in the human brain. These are debilitating and largely untreatable conditions that are strongly linked with age. Worldwide, around 50 million people are estimated to be living with Alzheimer’s disease and other forms of dementia, a number expected to double every 20 years. By 2050, in Europe alone, the cost burden for Alzheimer’s and Parkinson’s disease is estimated to surpass €350 billion per year, highlighting age related ND as one of the most urgent medical and societal challenges of our time.

About JPND

The EU Joint Programme - Neurodegenerative Disease Research (JPND) is the largest global research initiative aimed at tackling the challenge of neurodegenerative disease (ND). JPND aims to increase coordinated investment between participating countries in research aimed at finding causes, developing cures, and identifying appropriate ways to care for those with ND. The ultimate goal of JPND is to find cures for ND and to enable early diagnosis for early targeted treatments.

To view our privacy statement please click here.

Page 2: About this consultation

About this consultation

This consultation will guide you through and request your feedback on the different Scientific Priorities and Enabling Activities of the JPND Research and Innovation Strategy. Please note that the priorities and actions have been shortened for the purposes of this consultation and the full unabridged version of the JPND Research and Innovation Strategy can be viewed clicking here or on the link provided within each section.

Do I need to complete every section?

Some of the themes may be more relevant to specific stakeholder groups, though anyone is free to respond to any section. You can also skip a section by pressing the '*Next*' button at the bottom of each page. If you do not want to answer a specific point in the consultation please leave blank.

Can I save my responses?

If you have started the survey and would like to complete it at a later point, select the '*Finish Later*' link at the bottom of the page. Then follow the instructions to either bookmark the address or to email a link that will allow you to continue the survey by the date stated. Consultation responses can be submitted up to 11pm (GMT +1) on Monday 8th October when the consultation will close, it will not be possible to respond after this point.

Next Steps:

Your responses to the consultation will be taken into consideration by JPND during preparation of the updated *JPND Research and Innovation Strategy*, for publication in early 2019. In addition, we plan to publish the aggregate responses to the consultation within a summary report on the JPND website.

Troubleshooting and comments

If you have any problems accessing or using the survey please email consultation@jpnd.eu

Page 3: About you

1. Please select the category that best represents you or your organisation? ✱ *Required*

Please select at least 1 answer(s).

- ☐ Academic researcher
- ☐ Commercial researcher
- ☐ Charity organisation or patient group
- ☐ Funding agency, policy-maker or regulator
- ☐ Healthcare professional
- ☐ Person with a neurodegenerative condition or their carer
- ☐ General public or other

2. Do you consent to JPND publishing your/your organisation's response? ✱ *Required*

Please select exactly 1 answer(s).

- ☐ Yes, attributed to myself or my organisation
- ☐ Yes, only anonymously* (My replies can be published, but not any information identifying me as a respondent)
- ☐ No, I/we do not wish my/our response to be used other than in the overall analysis of responses

*If you select this option, you should ensure that your name does not appear in the main text of your response. JPND cannot take responsibility for anonymising responses in which the individual or organisation is identifiable from the content of their response.

3. Title ✱ *Required*

☐ Mr	☐ Mrs	☐ Ms
☐ Dr	☐ Professor	☐ Other

3.a. If you selected Other, please specify:

4. Contact email address ✱ *Required*

Please enter a valid email address.

5. First Name ✱ *Required*

Please enter a response that only contains letters.

6. Last Name ✱ *Required*

Please enter a response that only contains letters.

7. Country of residence *(one answer possible).* ✱ *Required*

Please select exactly 1 answer(s).

☐ Albania
☐ Austria
☐ Australia
☐ Belgium

☐ Bulgaria
☐ Canada
☐ Czech Republic
☐ Denmark
☐ Finland
☐ Germany
☐ Greece
☐ France
☐ Hungary
☐ Israel
☐ Ireland
☐ Italy
☐ Luxembourg
☐ the Netherlands
☐ Norway
☐ Poland
☐ Portugal
☐ Romania
☐ Slovakia
☐ Slovenia
☐ Spain
☐ Sweden
☐ Switzerland
☐ Turkey
☐ United Kingdom
☐ Other

7.a. If you selected Other, please specify:

8. May we include you on the JPND stakeholder database? This means we may contact you from time to time with the latest news from JPND. ✱ *Required*

○ Yes
○ No
○ I am already in the database

Page 4: Scientific Priorities

To achieve impact there is a need to encourage novel as well as multidisciplinary approaches, and to strengthen and extend existing capabilities across the full spectrum of basic, clinical, health and social care, and translational research.

The questions on the following pages ask for your views on JPND's priorities for future research across the different scientific themes below:

1. **The origins and progression of neurodegenerative disease.**
2. **Disease mechanisms and models.**
3. **Diagnosis, prognosis and disease definitions.**
4. **Developing therapies, preventive strategies and interventions.**
5. **Healthcare and social care**

Page 5: Theme One: Origins and progression of neurodegenerative disease

This theme focuses on improving our knowledge about the fundamental causes of specific neurodegenerative diseases (ND). This includes identifying the factors that determine people's risk and resilience and better understanding the triggering events leading to the onset and progression of disease.

Within this theme JPND has identified the following research priorities:

A. Better understand the significance of recently discovered risk factors for ND.

B. Identify new genetic, environmental and social risk factors for ND.

C. Deepen understanding of the causes of different protein misfolding disorders, a feature common to many ND, taking account of new and evolving technologies.

D. Understand ageing and how this relates to the development of and resilience to ND.

E. Optimise the use of data from existing population-based and ND-relevant cohorts and where possible repurpose or enrich cohorts with ND specific measures.

F. Promote studies investigating synapse dysfunction and loss in cognitive decline.

G. Expansion of research on post-mortem tissues from brain banks

H. Advance knowledge of the interactions between ND with vascular and metabolic systems and the role of infection and inflammation.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

9. Do you agree with these research priorities?

○ Agree
○ Undecided
○ Disagree

9.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

10. What would you like to see included that isn't covered in the above priorities? (please explain below)

11. Which priorities do you consider to be less important? (please explain below)

Page 6: Theme Two: Disease mechanisms and models

This theme focuses on improving our understanding of the biological basis underlying disease mechanisms and progression of neurodegenerative disease (ND). This includes the improvement of animal and cellular models of ND, together with taking advantage of developments in experimental medicine (investigations undertaken in humans).

Within this theme JPND has identified the following research priorities:

A. Develop novel animal models (ranging from worms to non-human primates) relevant to ND and take into account factors such as the progressive nature of ND, sex differences and ageing.

B. Establish cell-based models utilising innovative approaches to create disease specific and patient derived cell lines that better represent the complex pathology and interactions in ND.

C. Determine the role of new pathways proposed for ND pathogenesis e.g mechanisms of protein seeding (spreading).

D. Investigate traits, pathways, measures and biomarkers that are either common to, or specific for, different ND, spanning molecular-, cellular-, and systems-level approaches.

E. Identify the mechanism(s) that account for the effect of lifestyle factors on either promotion of resilience (e.g. educational enrichment in early life) or neurodegeneration.

F. Target emerging areas to better understand complex connections between biological systems that contribute to ND pathology (e.g develop models to investigate the contribution of the microbiome-gut-brain axis).

G. Elucidate the biological and environmental basis of behaviour and psychological symptoms in ND.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

12. Do you agree with these research priorities?

○ Agree

○ Undecided

○ Disagree

12.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

13. What would you like to see included that isn't covered in the above priorities? (please explain below)

14. Which priorities do you consider to be less important? (please explain below)

Page 7: Theme Three: Diagnosis, prognosis and disease definitions

This theme focuses on enhancing research relating to the definition and classification of neurodegenerative disease (ND), discovering new improved diagnostic techniques and identifying new biomarkers. Ultimately, this research will enable earlier and more accurate diagnosis of these diseases including the ability to predict disease progression and monitor the impact of therapies and interventions.

Within this theme JPND has identified the following research priorities:

A. Standardise disease definitions, diagnostic criteria, assessment tests and procedures for ND, developing and validating new ones where required.

B. Develop and validate new diagnostic criteria and procedures in a way that supports their implementation from the population level through to primary care and specialised clinical settings.

C. Harmonise and standardise existing biomarkers and develop, validate and standardise new biomarkers (e.g. molecular, imaging, functional, cognitive).

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

15. Do you agree with these research priorities?

○ Agree
○ Undecided
○ Disagree

15.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

16. What would you like to see included that isn't covered in the above priorities? (please explain below)

17. Which priorities do you consider to be less important? (please explain below)

Page 8: Theme Four: Developing therapies, preventive strategies and interventions

This theme focuses on the research needed to transform the treatment of neurodegenerative disease (ND). This includes the development of new therapies, intervention and prevention strategies (e.g. lifestyle modifications), defining better methods of care or a combination of these approaches at different intervention times.

Within this theme JPND has identified the following research priorities:

A. Improve the validity of model systems used for target identification and therapeutic development to increase the likelihood of translation to clinical benefit.

B. Investigate the differences and similarities in the susceptibility to neurodegeneration across specific neuronal subpopulations to reveal novel targets that may promote resilience and increase neuronal plasticity.

C. Ensure that population and disease based cohorts are used appropriately to target potential therapies to subgroups of patients most likely to respond and at the optimal stage in the disease continuum.

D. Develop disease modifying approaches, where appropriate, that slow, reduce, or clear the proteinopathy that underpins ND.

E. Promote regenerative strategies to restore function for ND where specific neuronal deficits are implicated.

F. Develop novel systems for delivery and targeting of drugs/biological agents to sites in the brain and other parts of the nervous system.

G. Promote research to consolidate and expand methods for the clinical assessment of human disease.

H. Encourage theoretical and empirical research and education regarding the use of non-pharmacological interventions such as cognitive training.

I. Encourage socio-economic studies that address ethical issues around how novel drugs are developed for ND; e.g., how best to undertake early phase clinical studies in ‘at-risk’ or presymptomatic individuals.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

18. Do you agree with these research priorities?

○ Agree
○ Undecided
○ Disagree

18.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

19. What would you like to see included that isn't covered in the above priorities? (please explain below)

20. Which priorities do you consider to be less important? (please explain below)

Page 9: Theme Five: Healthcare and social care

This theme focuses on research into the treatment, support and care of individuals with neurodegenerative disease (ND) together with their carers and families. Researchers should employ conceptually sound approaches to seek to understand the factors that contribute to social inclusion, civic participation, dignity, health-related quality of life (QoL) and wellbeing for individuals with ND and their families, and to consider comorbid conditions that often affect the delivery of treatment and care.

Within this theme JPND has identified the following research priorities:

A. Evaluate current and potential pathways to diagnosis, treatment, care and support relevant to ND globally, particularly by reference to effectiveness, cost-effectiveness and equity of access.

B. Investigate the interplay of biological, environmental, social, economic and other factors in the determination of cognitive decline and behavioural and psychological symptoms.

C. Determine the critical factors that affect disability and health-related QoL and wellbeing in ND, including evaluating approaches to better support carers.

D. Focus on a person-centred approach to care where those affected by ND are involved in the planning, development and monitoring of their own care and individual health needs and resources.

E. Promote research into end-of-life and palliative care for ND patients.

F. Investigate the ability of assisted living and health technologies to address the needs of individual patients with ND and their carers.

G. Examine ethical issues relating to ND care and research, for example, whether and how consent is sought and provided in relation to people with mental incapacity.

H. Conduct studies to determine how to improve access to formal care to reduce the unmet needs of individuals outside the formal care system.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

21. Do you agree with these research priorities?

○ Agree
○ Undecided
○ Disagree

21.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

22. What would you like to see included that isn't covered in the above priorities? (please explain below)

23. Which priorities do you consider to be less important? (please explain below)

Page 10: Enabling Activities

A number of cross-cutting activities will be needed to progress the scientific themes outlined previously. The questions on the following pages ask for your views on the different enabling activities below:

1. **Supportive infrastructure and platforms**
2. **Partnership with industry and fostering innovation**
3. **Working with Regulatory Organisations**
4. **International partnership**
5. **Capacity Building**
6. **Education and Training**
7. **Connection to policy makers**
8. **Communication and outreach**

Page 11: Theme One: Supportive infrastructure and platforms

This theme focuses on opportunities to harmonise many aspects of ND research and to develop an integrative approach across the dimensions of basic, clinical, healthcare and social science. The ability to do this is aided by recent advances in computational power and intelligence and increasing recognition of the strength of effective research collaboration and partnerships.

Accordingly JPND should seek to:

A. Encourage integration and harmonisation of data and materials and promote an open-access approach to sharing and pooling of data and resources.

B. Establish standardised methods, platforms and tools for data collection and analysis.

C. Support the development of multimodal imaging platforms for access to complementary information from different neuroimaging technologies, to improve convergence between preclinical and clinical research data.

D. Provide coherence to the global investment in cutting-edge but high-cost areas, such as proteomics and computational biology, to establish centres or networks at the national or international level.

E. Ensure wider access to high-quality biomaterials (e.g. brain tissue, from ND patients and from age-matched controls) provided through biobanks.

F. Link and better exploit existing cohorts, patient registers and sample/data collections.

G. Establish national and global registers of people with both common and rare forms of ND.

H. Promote registers of patients with cognitive impairment, with minimum requirements for entry, to reflect real-world situations.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

24. Do you agree with the actions outlined in this theme?

○ Agree

○ Undecided

○ Disagree

24.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

25. What would you like to see included that isn't covered in the above actions? (please explain below)

26. Which actions do you consider to be less important? (please explain below)

Page 12: Theme Two: Working in partnership with industry and fostering innovation

Many different commercial organisations engage with ND research, ranging from pharmaceutical, diagnostic, biotechnology, bioinformatics, imaging and digital health sectors to assisted living and healthcare providers, including the care home industry. Connection between and across academic and commercial domains is essential to deliver novel approaches to diagnosis, treatment and care. There are also opportunities to bring innovative and targeted products to market through partnerships with small and medium enterprises with expertise in specific areas. Effort is needed to:

A. Facilitate high-quality two-way collaboration between academic and industry sectors by paying greater attention to how innovative research and understanding of disease can support the needs of the global ND market.

B. Promote innovation within a multi-partner international funding framework by fostering a risk-taking approach and streamlining the pathway to accessing and exploiting innovative discoveries.

C. Develop approaches to give companies visibility and access to science opportunities emerging from academic research at the earliest stages, fostering co-development of innovation across sectors.

D. Foster a genuine collaborative culture with and between industry sectors, reflecting the emerging trend for industry to conduct less discovery science in-house.

E. Promote funding mechanisms for joint academic-industry research, specifically in the areas of data banking and data modelling, private-public collaboration for clinical trials and precompetitive research.

F. Continue collaborative, academic-industry partnerships for system level approaches to the study of the taxonomy of ND and for the development of new pharmaceuticals.

G. Encourage data and resource exchange between industry, clinical centres and academia, on both science and regulatory issues.

H. Support knowledge transfer between sectors, encouraging secondments and people exchange alongside development of shared campuses to support innovation.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

27. Do you agree with the actions outlined in this theme?

○ Agree
○ Undecided
○ Disagree

27.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

28. What would you like to see included that isn't covered in the above actions? (please explain below)

29. Which actions do you consider to be less important? (please explain below)

Page 13: Theme Three: Working with regulatory organisations

Effective translation of academic and commercial research into meaningful and beneficial treatments for patients requires dialogue and co-operation with key transnational and national regulatory agencies, as well as harmonisation across organisations. Maintaining the highest standards of ethics and governance will promote public confidence, as will the provision of up to date and clear guidance.

The following actions are needed to facilitate translation:

A. Promote interactions between researchers, clinicians, industry, patients, carers, families and regulatory organisations to inform key data collection and study design considerations at the earliest stages possible.

B. Promote the standardisation of procedures around the control and consent of patient data.

C. Work with regulators to integrate patient preference and patient-reported outcome information into all relevant stages of research and therapeutic development.

D. Re-examine research governance and regulation in relation to the unique aspects of ND; e.g., concerning studies in presymptomatic individuals.

E. Ensure that regulatory guidance is aligned with financial incentives and the practicalities of designing rigorous, definitive and statistically powerful clinical trials.

F. Encourage the acceptance of alternate trial designs where appropriate, optimising the use of resources and reducing the time to trial completion.

G. Promote the creation of support networks, public/private consortia and/or portals or hubs to disseminate best practices in regulation.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

30. Do you agree with the actions outlined in this theme?

○ Agree

○ Undecided

○ Disagree

30.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

31. What would you like to see included that isn't covered in the above actions? (please explain below)

32. Which actions do you consider to be less important? (please explain below)

Page 14: Theme Four: International partnership

It is now well recognised that the unmet clinical need and societal impact of ND is a global issue, and opportunities exist for JPND to link to worldwide research efforts in this area. Such co-operation should be strategically directed and offer clear benefit to JPND's objectives. Linkages might operate at different levels, for example, activity to:

A. Utilise resources and infrastructures outside Europe; e.g., connecting with large-scale initiatives that provide access to major genetic or epidemiological samples, datasets or emerging technologies.

B. Promote alignment with groups collecting data relevant to ND research, such as the World Health Organisation's Global Dementia Observatory.

C. Study specific populations in countries where unique genetic predispositions, specific or novel environmental exposures or societal/cultural differences might contribute to the risk, disease expression or resilience in ND.

D. Widen our understanding of how cultural differences affect the management of health delivery and social care.

E. Promote closer global alignment of patient and public involvement (PPI) and ethics activities.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

33. Do you agree with the activities outlined in this theme?

○ Agree
○ Undecided
○ Disagree

33.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

34. What would you like to see included that isn't covered in the above activities? (please explain below)

35. Which activities do you consider to be less important? (please explain below)

Page 15: Theme Five: Capacity Building

Across all three research domains of JPND there are certain areas that lack capacity and need to be strengthened to ensure future opportunities can be realised. Approaches to capacity building already used within JPND countries or internationally should be shared, with a view to identifying approaches that might be adapted to the specific needs identified below.

Accordingly, JPND needs to:

A. Encourage research networks across and between disciplines and researchers, both within individual countries and internationally.

B. Improve the training of clinical researchers, and translational specialists and ensure that their role is recognised and sustained.

C. Promote a culture of open science, data sharing and dissemination between global initiatives and teams developing resources for ND research.

D. Increase the numbers of neurodegeneration researchers, especially those with expertise in health economics, public health surveillance, statistics, computational biology, bioinformatics, electrophysiology and disease model development.

E. Support interdisciplinary research within existing frameworks and build new alliances across science and other research areas (e.g. physics, engineering, artificial intelligence).

F. Promote capability and improve the quality of digital technologies and devices (e.g. wearables) in terms of patient monitoring, risk prediction, diagnosis, clinical trials and treatment in large populations.

For further details on the above points please see the full version of the JPND Research and Innovation Strategy by clicking here.

36. Do you agree with the actions outlined in this theme?

○ Agree
○ Undecided
○ Disagree

36.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

37. What would you like to see included that isn't covered in the above actions? (please explain below)

38. Which actions do you consider to be less important? (please explain below)

Page 16: Theme Six: Education and Training

There is considerable heterogeneity in awareness amongst healthcare professionals and related stakeholder groups about the ways that people are affected by ND. An evidence-led educational approach will help to embed a research culture across the full spectrum of health and social care. It will also help to promote public health messaging, and lead to greater involvement in care. This strategy will help to reduce stigma and misunderstanding that surround these conditions.

Specific recommendations for education and training in relation to ND are to:

A. Expand the clinical education and training of health and social care professionals who interact with ND patients.

B. Promote appreciation amongst health and social care professionals of the benefits of research participation.

C. Undertake research to improve and implement effective health education to promote broader awareness about ND across all generations and sectors of society.

D. Understand how to create changes in behaviour in the population through strategies aimed at mitigating risk factors associated with an unhealthy lifestyle and lessening the chance of developing ND.

E. Develop systems for education and training that support recognition frameworks for researchers who share methods and data in a '*team science*' environment.

F. Promote opportunities to engage neurosurgeons in ND research to reinforce translational medicine.

G. Provide education for families and carers on new or existing technologies or devices that can promote freedom and independence of ND patients.

For further details on the above points please see the full version of the JPND Research and Innovation Agenda by clicking here.

39. Do you agree with the points and recommendations outlined in this theme?

○ Agree

○ Undecided

○ Disagree

39.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

40. What would you like to see included that isn't covered in the above recommendations? (please explain below)

41. Which recommendations do you consider to be less important? (please explain below)

Page 17: Theme Seven: Connection to policy makers

JPND provides a single international framework through which to highlight important current and emerging issues for policy consideration at the national level. One of the key aims of JPND is to promote compatibility between the policy approaches of different countries. There are two key translational gaps in ND-related policy where national policy makers can take action to improve the impact of research, and the quality of life, for patients, carers and their families. First, better links with technology developers are needed to ensure that the benefits of new technologies and practices are being extended to the patients and carers who most need them. Second, there is a need for national policy frameworks to ensure that research outcomes ultimately will lead to effective implementation in public health policy.

The following activities will be needed to enhance the progress made to date and help address ongoing challenges:

A. Strengthen the commitment of national governments to support ND research.

B. Expand the adoption of national plans for ND (general or specific).

C. Increase national earmarked budgets for transnational research.

D. Better facilitate resources, funds and data exchange across borders.

E. Adopt and harmonise evidence-based policies and best practices at the national level.

F. Promote effective communication between researchers and policy makers.

G. Increase awareness and understanding of the societal impact of ND.

For further details on the above points please see the full version of the JPND Research and Innovation Agenda by clicking here.

42. Do you agree with the activities outlined in this theme?

○ Agree
○ Undecided
○ Disagree

42.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

43. What would you like to see included that isn't covered in the above activities? (please explain below)

44. Which activities do you consider to be less important? (please explain below)

Page 18: Theme Eight: Communication and outreach

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

A. Disseminate ND research outcomes to all stakeholder communities in an effective, balanced and consistent manner to assist successful translation into policy and practice.

B. Consult the JPND PPI Stakeholder Advisory Board regarding JPND initiatives and research outcomes.

C. Increase awareness and support for ND research amongst decision makers in participating countries.

D. Encourage JPND-funded researchers to engage in dissemination and outreach activities as appropriate.

E. Promote the development of innovative tools to facilitate communication between individuals with ND, their families and carers, healthcare professionals, and care service providers.

F. Continue to support dialogue with stakeholder communities on a national and international level.

For further details on the above points please see the full version of the JPND Research and Innovation Agenda by clicking here.

45. Do you agree with the activities outlined in this theme?

○ Agree
○ Undecided
○ Disagree

45.a. Please comment on your response below:

Your answer should be no more than 1000 characters long.

46. What would you like to see included that isn't covered in the above activities? (please explain below)

47. Which activities do you consider to be less important? (please explain below)

Page 19: Thank you for your response

Thank you for submitting your views on the 2018 Research and Innovation Strategy, we appreciate your input and contribution, which will help to shape JPND's future priorities and investment in neurodegenerative disease research over the next 5-10 years and beyond.

All consultation questionnaires received are formally recorded and in accordance with data protection your personal details are used solely in connection with the consultation process. To view our privacy statement please click here.
