Directory of charity and patient group respondees

### Responses from organisations

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<tr>
<td>1411</td>
<td>French Federation for Brain Research (FRC) *</td>
<td>France</td>
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<tr>
<td>1437</td>
<td>Alzheimer's Research UK</td>
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<td>The Alzheimer Society of Ireland</td>
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<tr>
<td>1626</td>
<td>European Parkinson's Disease Association (EPDA)</td>
<td>European-wide</td>
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<td>Association France Alzheimer</td>
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<td>Alzheimerforeningen</td>
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<td>The Cure Parkinson's Trust</td>
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<td>European Federation of Neurological Associations (EFNA)</td>
<td>European-wide</td>
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* The French Federation for Brain Research made two submissions to the online consultation

### Anonymous responses from organisations

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### Responses from individuals

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### Anonymous responses from individuals

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One additional response was received from an organisation which requested that their submission be used for no other purpose than in the overall analysis of responses.
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   - Strongly Agree
b) Improve education and training of healthcare professionals
   - Strongly Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers
   - Strongly Agree
d) Increase training for translational and clinician-scientists
   - Strongly Agree
e) Increase numbers of post-doctoral level researchers
   - Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?
   a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   - Agree
b) Survey long-term care standards and provision across Europe
   - Agree
c) Research into the needs of carers
   - Agree
d) Research into care approaches including end of life decision-making
   - Agree
e) Rethink approaches to care
   - Agree
f) Understand and investigate influence of comorbidities
   - Strongly Agree
g) Conduct research into effects of nutrition and frailty
   - Agree
h) Determine cost-effectiveness of healthcare pathways
   - Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   h) Determine cost-effectiveness of healthcare pathways
Second Priority
   b) Survey long-term care standards and provision across Europe
Third Priority
   f) Understand and investigate influence of comorbidities on NDD

Question 3: How would you define “care”?*

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

* Question 3 is not fully visible in the image.
Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research  
Neutral
b) Promote development of non-pharmacological interventions  
Neutral
c) Conduct multi-centre primary prevention studies  
Agree
d) Ensure better patient selection/stratification  
Neutral
e) Rethink approach to therapeutics  
Agree
f) Support for high-risk projects  
Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing  
Agree
b) Improve understanding of disease stages  
Agree
c) Improve understanding of disease mechanisms  
Strongly Agree
d) Develop an improved understanding of the genetic basis for NDD  
Agree
e) Determine the importance of genetic and environmental risk factors  
Agree
f) Focus research on rare hereditary forms of disease  
Neutral
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups  
Agree
h) Develop more representative animal and cell-based models of disease  
Agree

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis  
Neutral
b) Redefine and harmonise clinical endpoints and outcomes  
Neutral
c) Develop new biomarkers
d) Consider regulatory approaches
Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
a) Improve access to, and sharing of, infrastructure and resources
Agree
b) Improve access to patient groups, samples and data
Agree
c) Improve data and sample collection
Strongly Agree
d) Develop a register of persons with cognitive impairment
Agree
e) Develop centres of excellence
Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
  e) Develop centres of excellence
Second Priority
  c) Improve data and sample collection
Third Priority
  a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
Agree
b) Ensure greater engagement with regulators
Agree
c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
Strongly Agree
d) Encourage industry to adopt a pre-competitive approach to research
Neutral
e) Rethink patent lifetime and conduct public-private clinical trials
Neutral
f) Review and update legislation on treatment
Strongly Agree
g) Review and update legislation on privacy and data disclosure
Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
Strongly Agree
b) Encourage open-access sharing of data and materials
Strongly Agree
c) Joint academic-industry funding models
Strongly Agree
d) Simplify funding application systems  
    Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding  
    Strongly Agree

Question 2: Please rank the suggestions in order of priority  
First Priority  
Second Priority  
Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   Strongly Agree
b) Improve education and training of healthcare professionals
   Strongly Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers
   Strongly Agree
d) Increase training for translational and clinician-scientists
   Strongly Agree
e) Increase numbers of post-doctoral level researchers
   Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?
   c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?
   **** Note on Q2(c): Strongly agree about overall numbers of researchers; not so sure that health economics is priority, bioinformatics more important.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Neutral
b) Survey long-term care standards and provision across Europe
   Agree
c) Research into the needs of carers
   Agree
d) Research into care approaches including end of life decision-making
   Neutral
e) Rethink approaches to care
   Neutral
f) Understand and investigate influence of comorbidities
   Strongly Agree
g) Conduct research into effects of nutrition and frailty
   Agree
h) Determine cost-effectiveness of healthcare pathways
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
   First Priority
   f) Understand and investigate influence of comorbidities on NDD
   Second Priority
   g) Conduct research into effects of nutrition and frailty
   Third Priority
   e) Rethink approaches to care

Question 3: How would you define “care”?
   I don't have a firm definition
Question 4: Have you any (additional) suggestions as to how care systems should be revised?

I think we should promote whatever the evidence shows whilst highlighting where gaps exist.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research
   Agree
b) Promote development of non-pharmacological interventions
   Agree
c) Conduct multi-centre primary prevention studies
   Agree
d) Ensure better patient selection/stratification
   Agree
e) Rethink approach to therapeutics
   Agree
f) Support for high-risk projects
   Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Increase involvement of individuals in research
Second Priority
   d) Ensure better patient selection/stratification
Third Priority
   c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
We should look at what is already working - from registers of people who agree to take part in research, to embedding research capability within healthcare services. There are several brain donation initiatives e.g. Brains for Dementia Research and the Parkinson's brainbank in the UK - we can learn from these.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?
I think the most important aspect is time. Hard as it is for funding agencies, any studies looking at modifiable risk factors in mid-life need to have long-term follow up to be of any value.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
   Agree
b) Improve understanding of disease stages
   Agree
c) Improve understanding of disease mechanisms
   Strongly Agree
d) Develop an improved understanding of the genetic basis for NDD
   Strongly Agree
e) Determine the importance of genetic and environmental risk factors
   Strongly Agree
f) Focus research on rare hereditary forms of disease
   Neutral
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
   Strongly Agree
h) Develop more representative animal and cell-based models of disease
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   c) Improve understanding of disease mechanisms
Second Priority
   e) Determine the importance of genetic and environmental risk factors
Third Priority
   g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

This could be acceptable if the aspect of the disease pathology being researched cannot be modelled in any animal. The jury seems to be out on the predictive value of rodent models of AD at the moment, which could either be used as a reason to discount them altogether, or to provide a spur to find better ones. The latter approach seems better in the short term at least.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis
   Agree

b) Redefine and harmonise clinical endpoints and outcomes
   Strongly Agree

c) Develop new biomarkers
   Strongly Agree

d) Consider regulatory approaches
   Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?
   b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
a) Improve access to, and sharing of, infrastructure and resources
   Agree

b) Improve access to patient groups, samples and data
   Agree

C) Improve data and sample collection
   Strongly Agree

d) Develop a register of persons with cognitive impairment
   Strongly Agree

e) Develop centres of excellence
   Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
   d) Develop a register of persons with cognitive impairment

Second Priority
   a) Improve access to, and sharing of, infrastructure and resources

Third Priority
   c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?
   The ADNI model seems to have worked well.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   As above. This is something which funders can take a collective lead on.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   What is the evidence that this is the best use of money? These things can get mired in 'politics'.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
   Strongly Agree

b) Ensure greater engagement with regulators
   Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
   Agree

d) Encourage industry to adopt a pre-competitive approach to research
   Agree

e) Rethink patent lifetime and conduct public-private clinical trials
   Neutral
f) Review and update legislation on treatment
   Agree

g) Review and update legislation on privacy and data disclosure
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Need for evidence-based policy
Second Priority
   d) Encourage industry to adopt pre-competitive approach
Third Priority
   b) Ensure greater engagement with regulators

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?
   This is being looked at in the UK at the moment - looking at where unnecessary 'red tape' may be cut. Local ethics approvals seem to be in need of attention. A single regulator for clinical research may also help.

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
   Strongly Agree
b) Encourage open-access sharing of data and materials
   Strongly Agree
c) Joint academic-industry funding models
   Agree
d) Simplify funding application systems
   Neutral
e) Maintain capacity for 'bottom-up' innovative funding
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   e) Maintain capacity for 'bottom-up' innovative funding
Second Priority
   a) Translational research needs to be promoted
Third Priority
   b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal
   As funders the word 'Encourage' could be changed to 'Enforce'.

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
   Co-ordination of the European NDD research effort is a worthwhile venture only if it is followed by/accompanied by significant European funding. More researchers from a whole spectrum of disciplines are needed to work in this field and it wont happen by itself.
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   Agree
b) Improve education and training of healthcare professionals
   Strongly Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers
   Strongly Agree
d) Increase training for translational and clinician-scientists
   Strongly Agree
e) Increase numbers of post-doctoral level researchers
   Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?
   b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Agree
b) Survey long-term care standards and provision across Europe
   Agree
c) Research into the needs of carers
   Agree
d) Research into care approaches including end of life decision-making
   Strongly Agree
e) Rethink approaches to care
   Strongly Agree
f) Understand and investigate influence of comorbidities
   Strongly Agree
g) Conduct research into effects of nutrition and frailty
   Agree
h) Determine cost-effectiveness of healthcare pathways
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   h) Determine cost-effectiveness of healthcare pathways
Second Priority
e) Rethink approaches to care
d) Research end of life decision making
Third Priority

Question 3: How would you define “care”?
I think we need to define care according to those who provide it - i.e paid professional carers or family carers (informal carers)
Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Care at home should be part of a suite of services available to the person with NDD; there should be an integrated care pathway developed combining all of the clinical and care elements in an integrated fashion with joined up planning and a co-ordinated approach.

**Prevention/treatment strategies and trials**

**Question 1:** Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research
   Strongly Agree

b) Promote development of non-pharmacological interventions
   Strongly Agree

c) Conduct multi-centre primary prevention studies
   Strongly Agree

d) Ensure better patient selection/stratification
   Agree

e) Rethink approach to therapeutics
   Strongly Agree

f) Support for high-risk projects
   Agree

**Question 2:** Please rank the suggestions in order of priority

**First Priority**
   e) Rethink approach to therapeutics

**Second Priority**
   b) Promote development of non-pharmacological interventions

**Third Priority**
   a) Increase involvement of individuals in research

**Question 3:** How can we encourage more people to take part in research and/or register to donate brain material?

We need to be able to 'sell' the benefits to the patient and their family in a much more accessible way. The Health Care Professional involved in the care of that person is a critical influencer and they need to be bought into the research agenda.

**Question 4:** If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

**Disease cause, mechanisms and models**

**Question 1:** Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing
   Strongly Agree

b) Improve understanding of disease stages
   Strongly Agree

c) Improve understanding of disease mechanisms
   Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD
   Agree

e) Determine the importance of genetic and environmental risk factors
   Agree

f) Focus research on rare hereditary forms of disease
   Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
   Agree

h) Develop more representative animal and cell-based models of disease
   Agree

**Question 2:** Please rank the suggestions in order of priority

**First Priority**
   a) Understand relationship between NDD and ageing

**Second Priority**
   b) Improve understanding of disease stages

**Third Priority**
   c) Improve understanding of disease mechanisms

**Question 3:** In relation to disease mechanisms which of the following do you think it is most important to investigate?
Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

**Diagnosis, disease definitions and outcome measures**

Question 1: Please indicate to what extent you endorse the following points
- a) Redefine and standardise disease definitions and diagnosis
  - Strongly Agree
- b) Redefine and harmonise clinical endpoints and outcomes
  - Strongly Agree
- c) Develop new biomarkers
  - Strongly Agree
- d) Consider regulatory approaches
  - Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?
  - b) Linking to treatment responses

**Data, registries, repositories and centres**

Question 1: Please indicate to what extent you endorse the following points
- a) Improve access to, and sharing of, infrastructure and resources
  - Strongly Agree
- b) Improve access to patient groups, samples and data
  - Strongly Agree
- c) Improve data and sample collection
  - Strongly Agree
- d) Develop a register of persons with cognitive impairment
  - Strongly Agree
- e) Develop centres of excellence
  - Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
- d) Develop a register of persons with cognitive impairment
Second Priority
- a) Improve access to, and sharing of, infrastructure and resources
Third Priority
- c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

**Policy, regulation and legislation**

Question 1: Please indicate to what extent you endorse the following points
- a) Need for evidence-based policy
- b) Ensure greater engagement with regulators
- c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
- d) Encourage industry to adopt a pre-competitive approach to research
- e) Rethink patent lifetime and conduct public-private clinical trials
- f) Review and update legislation on treatment
- g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

**Funding and funding mechanisms**
Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
b) Encourage open-access sharing of data and materials
c) Joint academic-industry funding models
d) Simplify funding application systems
e) Maintain capacity for ‘bottom-up’ innovative funding

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
**Education, training and collaboration**

**Question 1:** Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population  
   - Strongly Agree
b) Improve education and training of healthcare professionals  
   - Strongly Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers  
   - Agree
d) Increase training for translational and clinician-scientists  
   - Strongly Agree
e) Increase numbers of post-doctoral level researchers  
   - Agree

**Question 2:** If you had to choose one priority from the points above what would it be?

- b) Improve education and training of healthcare professionals

**Question 3:** Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Improve dialogue between researchers and the wider population to achieve better general awareness and knowledge of research and increase understanding of how participation can improve research quality and progress. To reduce the many hurdles that exist within the long and complex process of progressing a new treatment from the laboratory bench to the bedside.

**Health and social care issues**

**Question 1:** Please indicate to what extent you endorse the following points

a) Define the term “care”  
   - Agree
b) Survey long-term care standards and provision across Europe  
   - Strongly Agree
c) Research into the needs of carers  
   - Strongly Agree
d) Research into care approaches including end of life decision-making  
   - Strongly Agree
e) Rethink approaches to care  
   - Strongly Agree
f) Understand and investigate influence of comorbidities  
   - Strongly Agree
g) Conduct research into effects of nutrition and frailty  
   - Strongly Agree
h) Determine cost-effectiveness of healthcare pathways  
   - Strongly Agree

**Question 2:** Please rank the suggestions in order of priority

**First Priority**
- e) Rethink approaches to care

**Second Priority**
- h) Determine cost-effectiveness of healthcare pathways

**Third Priority**
- a) Define the term ‘care’
Question 3: How would you define “care”?
Many people with Parkinson’s believe ‘gold standard care’ should involve a multidisciplinary team with care tailored to their specific needs and those of their family and carers. Such multidisciplinary treatment may involve a number of allied health specialists, including physiotherapists, occupational therapists and speech and language therapists as well as support and advice from dieticians, social workers and sexologists to complement standard medical treatment in the management of both motor and non-motor symptoms. While the neurologist determines disease severity and optimises medical treatment to reduce symptoms, allied health therapists work to minimise the impact of the disease process and improve the person’s participation in everyday activities.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
For care to be as effective as possible it needs to be integrated so that all those involved work together as a team. This can be a complex challenge but increasingly there are palliative care strategies (also known as ‘care pathways’) in place to ensure effective and quality care. These support the patient, their family and the multidisciplinary team in planning and delivering coordinated, seamless and prompt care, according to need, ensuring all parties are actively involved. Across Europe, the degree to which the different elements of palliative care are integrated and coordinated varies considerably, but where such integration exists, access to palliative care is much simpler and beneficial for everyone.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Advocate for change with the decision makers that it is cost effective for people to remain within their home setting and to receive the necessary care. This not only improves quality of life but also has a huge reduction on the cost of care within the individual country health systems. See Movement Disorders Vol 18, No. 10, 2003:1139-1189, Direct Economic Impact of Parkinson's Disease: A Research Survey in the United Kingdom. To educate healthcare and social services to inform of the options available for support within the home.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research
Agree

b) Promote development of non-pharmacological interventions
Strongly Agree

c) Conduct multi-centre primary prevention studies
Agree

d) Ensure better patient selection/stratification
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
  e) Rethink approach to therapeutics

Second Priority
  b) Promote development of non-pharmacological interventions

Third Priority
  f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
There is a great deal of mis-conception serious lack of understanding as to the importance and necessity for research and donation of brain material. Therefore there should be an innovative and improved focus on awareness and education to the general public to dispel the myths.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing
Agree

b) Improve understanding of disease stages
Strongly Agree

c) Improve understanding of disease mechanisms
Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD
Strongly Agree

e) Determine the importance of genetic and environmental risk factors
Strongly Agree
f) Focus research on rare hereditary forms of disease
   Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in
   high risk groups
   Strongly Agree

h) Develop more representative animal and cell-based models of disease
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   b) Improve understanding of disease stages

Second Priority
   c) Improve understanding of disease mechanisms

Third Priority
   d) Develop an improved understanding of the genetic basis

Question 3: In relation to disease mechanisms which of the following do you think it is most
   important to investigate?
   c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based
   models straight to humans (i.e. missing out animal models)? If so please explain under what
   circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis
   Disagree

b) Redefine and harmonise clinical endpoints and outcomes
   Disagree

c) Develop new biomarkers
   Strongly Agree

d) Consider regulatory approaches
   Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?
   b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
a) Improve access to, and sharing of, infrastructure and resources
   Strongly Agree

b) Improve access to patient groups, samples and data
   Strongly Agree

c) Improve data and sample collection
   Strongly Agree

d) Develop a register of persons with cognitive impairment
   Neutral

e) Develop centres of excellence
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   b) Improve access to patient groups, samples and data

Second Priority
   c) Improve data and sample collection

Third Priority
   a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we
   overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   By developing centres of excellence it could result in ‘only’ the few being involved and diluted resources
   available in other regions.

Policy, regulation and legislation
Question 1: Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
   Neutral
b) Ensure greater engagement with regulators
   Agree
c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
   Agree
d) Encourage industry to adopt a pre-competitive approach to research
   Agree
e) Rethink patent lifetime and conduct public-private clinical trials
   Agree
f) Review and update legislation on treatment
   Agree
g) Review and update legislation on privacy and data disclosure
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   g) Review and update legislation on privacy and data disclosure
Second Priority
   b) Ensure greater engagement with regulators
Third Priority
   d) Encourage industry to adopt pre-competitive approach

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
   Neutral
b) Encourage open-access sharing of data and materials
   Neutral
c) Joint academic-industry funding models
   Agree
d) Simplify funding application systems
   Agree
e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority
First Priority
   c) Joint academic-industry funding models
Second Priority
   d) Simplify funding application systems
Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
  a) Improve dialogue between researchers and the wider population
     Agree
  b) Improve education and training of healthcare professionals
     Strongly Agree
  c) Increase numbers of neurodegenerative disease (NDD) researchers
     Agree
  d) Increase training for translational and clinician-scientists
     Agree
  e) Increase numbers of post-doctoral level researchers
     Agree

Question 2: If you had to choose one priority from the points above what would it be?
  c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?
  Improve education and training of healthcare professionals

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
  a) Define the term “care”
     Agree
  b) Survey long-term care standards and provision across Europe
     Agree
  c) Research into the needs of carers
     Agree
  d) Research into care approaches including end of life decision-making
     Agree
  e) Rethink approaches to care
     Agree
  f) Understand and investigate influence of comorbidities
     Agree
  g) Conduct research into effects of nutrition and frailty
     Agree
  h) Determine cost-effectiveness of healthcare pathways
     Agree

Question 2: Please rank the suggestions in order of priority
First Priority
  d) Research end of life decision making
Second Priority
  g) Conduct research into effects of nutrition and frailty
Third Priority
  f) Understand and investigate influence of comorbidities on NDD

Question 3: How would you define “care”?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
including the population at the beginning of the disease.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
  
  transferring of training between professionals and family carers

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research
  Agree
b) Promote development of non-pharmacological interventions
  Strongly Agree
c) Conduct multi-centre primary prevention studies
  Strongly Agree
d) Ensure better patient selection/stratification
  Agree
e) Rethink approach to therapeutics
  Agree
f) Support for high-risk projects
  Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
  b) Promote development of non-pharmacological interventions
Second Priority
  c) Conduct multi-centre primary prevention studies
Third Priority
  a) Increase involvement of individuals in research

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
  developing a new communication strategy towards the population

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?
  measures about cognitive aspect, physical aspect and nutritional aspect

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing
  Agree
b) Improve understanding of disease stages
  Agree
c) Improve understanding of disease mechanisms
  Agree
d) Develop an improved understanding of the genetic basis for NDD
  Agree
e) Determine the importance of genetic and environmental risk factors
  Agree
f) Focus research on rare hereditary forms of disease
  Agree
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
  Agree
h) Develop more representative animal and cell-based models of disease
  Agree

Question 2: Please rank the suggestions in order of priority

First Priority
  a) Understand relationship between NDD and ageing
Second Priority
  c) Improve understanding of disease mechanisms
Third Priority
  g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable.

**Diagnosis, disease definitions and outcome measures**

**Question 1:** Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis
   - Agree
b) Redefine and harmonise clinical endpoints and outcomes
   - Agree
c) Develop new biomarkers
   - Agree
d) Consider regulatory approaches
   - Agree

**Question 2:** Which of the following do you think is most important in terms of biomarkers?
   a) Linking to the mechanism of disease and functional endpoints

**Data, registries, repositories and centres**

**Question 1:** Please indicate to what extent you endorse the following points
a) Improve access to, and sharing of, infrastructure and resources
   - Agree
b) Improve access to patient groups, samples and data
   - Agree
c) Improve data and sample collection
   - Agree
d) Develop a register of persons with cognitive impairment
   - Neutral
e) Develop centres of excellence
   - Agree

**Question 2:** Please rank the suggestions in order of priority

**First Priority**
- e) Develop centres of excellence

**Second Priority**
- a) Improve access to, and sharing of, infrastructure and resources

**Third Priority**
- b) Improve access to patient groups, samples and data

**Question 3:** What can be done to facilitate increased sharing of data?

**Question 4:** What are your views on making data open access? If you foresee difficulties, how can we overcome these?

**Question 5:** Relating to point (e) do you see any risk(s) in developing centres of excellence?
   - no

**Policy, regulation and legislation**

**Question 1:** Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
   - Agree
b) Ensure greater engagement with regulators
   - Agree
c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
   - Agree
d) Encourage industry to adopt a pre-competitive approach to research
   - Neutral
e) Rethink patent lifetime and conduct public-private clinical trials
   - Neutral
f) Review and update legislation on treatment
   - Neutral
g) Review and update legislation on privacy and data disclosure
   - Agree

**Question 2:** Please rank the suggestions in order of priority

**First Priority**
- a) Need for evidence-based policy
Second Priority
   c) Facilitate research in areas outside university and hospital sectors

Third Priority
   g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
   Agree
b) Encourage open-access sharing of data and materials
   Neutral
c) Joint academic-industry funding models
   Agree
d) Simplify funding application systems
   Neutral
e) Maintain capacity for 'bottom-up' innovative funding
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   c) Joint academic-industry funding models
Second Priority
   a) Translational research needs to be promoted
Third Priority
   e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
**Education, training and collaboration**

**Question 1:** Please indicate to what extent you endorse the following points

- a) Improve dialogue between researchers and the wider population  
  *Strongly Agree*
- b) Improve education and training of healthcare professionals  
  *Strongly Agree*
- c) Increase numbers of neurodegenerative disease (NDD) researchers  
  *Strongly Agree*
- d) Increase training for translational and clinician-scientists  
  *Strongly Agree*
- e) Increase numbers of post-doctoral level researchers  
  *Agree*

**Question 2:** If you had to choose one priority from the points above what would it be?

  b) Improve education and training of healthcare professionals

**Question 3:** Are there any other specialist areas which you think need promoting or should be given greater emphasis?

**Health and social care issues**

**Question 1:** Please indicate to what extent you endorse the following points

- a) Define the term “care”  
  *Agree*
- b) Survey long-term care standards and provision across Europe  
  *Neutral*
- c) Research into the needs of carers  
  *Strongly Agree*
- d) Research into care approaches including end of life decision-making  
  *Neutral*
- e) Rethink approaches to care  
  *Strongly Agree*
- f) Understand and investigate influence of comorbidities  
  *Agree*
- g) Conduct research into effects of nutrition and frailty  
  *Agree*
- h) Determine cost-effectiveness of healthcare pathways  
  *Agree*

**Question 2:** Please rank the suggestions in order of priority

- **First Priority**
  c) Research into the needs of carers

- **Second Priority**
  e) Rethink approaches to care

- **Third Priority**
  h) Determine cost-effectiveness of healthcare pathways

**Question 3:** How would you define “care”?

To ensure the wellbeing of the person with dementia. It should be seen in a bio-psycho-societal context. Possibilities for the demented person to live as full a life as possible at each actual stage of the disease is
important. So care differs through the course of the disease. Support in the start, later more care in the usual content of the word is needed.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
No

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Educating and support for the relatives in day to day problems. Periods of relief, both shorter periods on a daily/weekly basis and longer spells of holiday. Hotlines to professional carers for advice in difficult situation Groups for relatives who can support each other.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research
Strongly Agree
b) Promote development of non-pharmacological interventions
Strongly Agree
c) Conduct multi-centre primary prevention studies
Strongly Agree
d) Ensure better patient selection/stratification
Neutral
e) Rethink approach to therapeutics
Strongly Agree
f) Support for high-risk projects

Question 2: Please rank the suggestions in order of priority
First Priority
e) Rethink approach to therapeutics

Second Priority
b) Promote development of non-pharmacological interventions

c) Conduct multi-centre primary prevention studies

Third Priority
c) Conduct multi-centre primary prevention studies
f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
More information about the possibilities to enregister into trials with new medicin. And more information about the how important it is to have material from brains, both normal and diseased, to help solve the riddle of the causes for dementia. So overall: information to the public and more specific to groups of patients and their relatives.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?
The effect of physical exercise on the development of dementia.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
Neutral
b) Improve understanding of disease stages
Strongly Agree
c) Improve understanding of disease mechanisms
Strongly Agree
d) Develop an improved understanding of the genetic basis for NDD
Agree
e) Determine the importance of genetic and environmental risk factors
Strongly Agree
f) Focus research on rare hereditary forms of disease
Neutral
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
Strongly Agree
h) Develop more representative animal and cell-based models of disease
Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
c) Improve understanding of disease mechanisms

Second Priority
b) Improve understanding of disease stages
Third Priority
  g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
  c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable
  No

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
  a) Redefine and standardise disease definitions and diagnosis
     Strongly Agree
  b) Redefine and harmonise clinical endpoints and outcomes
     Strongly Agree
  c) Develop new biomarkers
     Strongly Agree
  d) Consider regulatory approaches
     Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?
  c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
  a) Improve access to, and sharing of, infrastructure and resources
     Strongly Agree
  b) Improve access to patient groups, samples and data
     Strongly Agree
  c) Improve data and sample collection
     Strongly Agree
  d) Develop a register of persons with cognitive impairment
     Strongly Agree
  e) Develop centres of excellence
     Strongly Agree

Question 2: Please rank the suggestions in order of priority
  First Priority
    b) Improve access to patient groups, samples and data
  Second Priority
    e) Develop centres of excellence
  Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
  There could be a risk of missing out on new and unconventional ideas generated outside the centers.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
  a) Need for evidence-based policy
     Strongly Agree
  b) Ensure greater engagement with regulators
     Neutral
  c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
     Neutral
  d) Encourage industry to adopt a pre-competitive approach to research
     Strongly Agree
  e) Rethink patent lifetime and conduct public-private clinical trials
     Neutral
  f) Review and update legislation on treatment
g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

**Funding and funding mechanisms**

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
   Strongly Agree
b) Encourage open-access sharing of data and materials
   Strongly Agree
c) Joint academic-industry funding models
   Strongly Agree
d) Simplify funding application systems
   Strongly Agree
e) Maintain capacity for 'bottom-up' innovative funding
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

**Concluding questions**

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
**Education, training and collaboration**

**Question 1:** Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population  
   - Strongly Agree
b) Improve education and training of healthcare professionals  
   - Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers  
   - Strongly Agree
d) Increase training for translational and clinician-scientists  
   - Strongly Agree
e) Increase numbers of post-doctoral level researchers  
   - Strongly Agree

**Question 2:** If you had to choose one priority from the points above what would it be?  
   - d) Increase training for translational and clinician-scientists

**Question 3:** Are there any other specialist areas which you think need promoting or should be given greater emphasis?

**Health and social care issues**

**Question 1:** Please indicate to what extent you endorse the following points

a) Define the term “care”  
   - Neutral
b) Survey long-term care standards and provision across Europe  
   - Agree
c) Research into the needs of carers  
   - Agree
d) Research into care approaches including end of life decision-making  
   - Agree
e) Rethink approaches to care  
   - Agree
f) Understand and investigate influence of comorbidities  
   - Strongly Agree
g) Conduct research into effects of nutrition and frailty  
   - Strongly Agree
h) Determine cost-effectiveness of healthcare pathways  
   - Agree

**Question 2:** Please rank the suggestions in order of priority

**First Priority**
   - f) Understand and investigate influence of comorbidities on NDD

**Second Priority**
   - g) Conduct research into effects of nutrition and frailty

**Third Priority**
   - h) Determine cost-effectiveness of healthcare pathways

**Question 3:** How would you define “care”?  
   - Concern to do all that is required to support the health and comfort of a person with a condition

**Question 4:** Have you any (additional) suggestions as to how care systems should be revised?
Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research  
   Strongly Agree
b) Promote development of non-pharmacological interventions  
   Agree
c) Conduct multi-centre primary prevention studies  
   Strongly Agree
d) Ensure better patient selection/stratification  
   Strongly Agree
e) Rethink approach to therapeutics  
   Strongly Agree
f) Support for high-risk projects  
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority  
   e) Rethink approach to therapeutics
Second Priority  
   a) Increase involvement of individuals in research
Third Priority  
   d) Ensure better patient selection/stratification

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?  
   There are numerous advantages to individuals taking part in trials including a greater understanding of their own condition, leading to better health, and frequency of appointments. Within the Parkinson's world, many would like to take part but entry criteria make it difficult, as does location. Initiatives such as a Fox Trial Finder are the first step which would be an invaluable tool in Europe.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing  
   Agree
b) Improve understanding of disease stages  
   Agree
c) Improve understanding of disease mechanisms  
   Strongly Agree
d) Develop an improved understanding of the genetic basis for NDD  
   Strongly Agree
e) Determine the importance of genetic and environmental risk factors  
   Strongly Agree
f) Focus research on rare hereditary forms of disease  
   Agree
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups  
   Strongly Agree
h) Develop more representative animal and cell-based models of disease  
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority  
   c) Improve understanding of disease mechanisms
Second Priority  
   e) Determine the importance of genetic and environmental risk factors
Third Priority  
   a) Understand relationship between NDD and ageing

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?  
   a) Interactions between cells and their surrounding intra- and extracellular environment
Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable.

Absolutely, particularly with drugs being used in other therapeutic areas and compounds that occur naturally in humans such as hormones.

**Diagnosis, disease definitions and outcome measures**

**Question 1:** Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis
   - Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes
   - Strongly Agree

c) Develop new biomarkers
   - Strongly Agree

d) Consider regulatory approaches
   - Agree

**Question 2:** Which of the following do you think is most important in terms of biomarkers?

- c) Providing an indicator of, and sensitivity to, disease progression

**Data, registries, repositories and centres**

**Question 1:** Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources
   - Strongly Agree

b) Improve access to patient groups, samples and data
   - Strongly Agree

c) Improve data and sample collection
   - Strongly Agree

d) Develop a register of persons with cognitive impairment
   - Agree

e) Develop centres of excellence
   - Strongly Agree

**Question 2:** Please rank the suggestions in order of priority

First Priority
- b) Improve access to patient groups, samples and data

Second Priority
- e) Develop centres of excellence

Third Priority
- a) Improve access to, and sharing of, infrastructure and resources

**Question 3:** What can be done to facilitate increased sharing of data?

- Link national patient records across Europe - an IT issue

**Question 4:** What are your views on making data open access? If you foresee difficulties, how can we overcome these?

- Ensure patients own the data and are linked with appropriate research bodies to share this data

**Question 5:** Relating to point (e) do you see any risk(s) in developing centres of excellence?

- None

**Policy, regulation and legislation**

**Question 1:** Please indicate to what extent you endorse the following points

a) Need for evidence-based policy
   - Agree

b) Ensure greater engagement with regulators
   - Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
   - Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research
   - Agree

e) Rethink patent lifetime and conduct public-private clinical trials
   - Strongly Agree

f) Review and update legislation on treatment
   - Agree

g) Review and update legislation on privacy and data disclosure
   - Agree
Question 2: Please rank the suggestions in order of priority
First Priority
  e) Rethink patent lifetime and conduct public-private clinical trials
Second Priority
  d) Encourage industry to adopt pre-competitive approach
Third Priority
  b) Ensure greater engagement with regulators

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?
  Innovation Awards - fast track a set number of innovative approaches/treatments through the regulatory process using the MHRA's Early Access Scheme to pilot the scheme and prove its value to the industry and more importantly to patients who are desperate to receive the best treatments as quickly as possible.

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
  a) Translational research needs to be promoted
     Strongly Agree
  b) Encourage open-access sharing of data and materials
     Strongly Agree
  c) Joint academic-industry funding models
     Strongly Agree
  d) Simplify funding application systems
     Agree
  e) Maintain capacity for 'bottom-up' innovative funding
     Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
  c) Joint academic-industry funding models
Second Priority
  a) Translational research needs to be promoted
Third Priority
  e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal
  We have a plan - do contact us

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   Agree
b) Improve education and training of healthcare professionals
   Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers
   Strongly Agree
d) Increase training for translational and clinician-scientists
   Strongly Agree
e) Increase numbers of post-doctoral level researchers
   Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?
   a) Improve dialogue between researchers and the wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?
   A government national information campaign promoting the necessity for more funds to be invested in neurosciences.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Agree
b) Survey long-term care standards and provision across Europe
   Agree
c) Research into the needs of carers
   Agree
d) Research into care approaches including end of life decision-making
   Strongly Agree
e) Rethink approaches to care
   Strongly Agree
f) Understand and investigate influence of comorbidities
   Agree
g) Conduct research into effects of nutrition and frailty
   Neutral
h) Determine cost-effectiveness of healthcare pathways
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   h) Determine cost-effectiveness of healthcare pathways
Second Priority
   b) Survey long-term care standards and provision across Europe
Third Priority
   d) Research end of life decision making
Question 3: How would you define “care”?
Trying to help patients not to suffer, keeping their dignity, end their life being listened, understood and respected.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Enable families who accept to take care of patients at their home to find a dedicated place to “make a break”, tell their fears and difficulties, and be supported by professionals trained for that.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research
   Neutral
b) Promote development of non-pharmacological interventions
   Agree
c) Conduct multi-centre primary prevention studies
   Neutral
d) Ensure better patient selection/stratification
   Neutral
e) Rethink approach to therapeutics
   Agree
f) Support for high-risk projects
   Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Increase involvement of individuals in research
Second Priority
   e) Rethink approach to therapeutics
Third Priority
   b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
   information, education

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
   Neutral
b) Improve understanding of disease stages
   Agree
c) Improve understanding of disease mechanisms
   Strongly Agree
d) Develop an improved understanding of the genetic basis for NDD
   Neutral
e) Determine the importance of genetic and environmental risk factors
   Neutral
f) Focus research on rare hereditary forms of disease
   Neutral
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
   Agree
h) Develop more representative animal and cell-based models of disease
   Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
   g) Establish pan-European population-based studies
Second Priority
   c) Improve understanding of disease mechanisms
Third Priority
   b) Improve understanding of disease stages
Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
   a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
   a) Redefine and standardise disease definitions and diagnosis
      Neutral
   b) Redefine and harmonise clinical endpoints and outcomes
      Agree
   c) Develop new biomarkers
      Neutral
   d) Consider regulatory approaches
      Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?
   c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
   a) Improve access to, and sharing of, infrastructure and resources
      Agree
   b) Improve access to patient groups, samples and data
      Agree
   c) Improve data and sample collection
      Agree
   d) Develop a register of persons with cognitive impairment
      Neutral
   e) Develop centres of excellence
      Strongly Agree

Question 2: Please rank the suggestions in order of priority
   First Priority
      e) Develop centres of excellence
   Second Priority
      b) Improve access to patient groups, samples and data
   Third Priority
      a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you forsee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
   a) Need for evidence-based policy
      Neutral
   b) Ensure greater engagement with regulators
      Neutral
   c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
      Agree
   d) Encourage industry to adopt a pre-competitive approach to research
      Neutral
   e) Rethink patent lifetime and conduct public-private clinical trials
      Agree
   f) Review and update legislation on treatment
      Agree
   g) Review and update legislation on privacy and data disclosure
      Agree
Question 2: Please rank the suggestions in order of priority

First Priority
  e) Rethink patent lifetime and conduct public-private clinical trials

Second Priority
  f) Review and update legislation on treatment

Third Priority
  g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
   Strongly Agree
b) Encourage open-access sharing of data and materials
   Agree
c) Joint academic-industry funding models
   Agree
d) Simplify funding application systems
   Strongly Agree
e) Maintain capacity for 'bottom-up' innovative funding
   Agree

Question 2: Please rank the suggestions in order of priority

First Priority
  a) Translational research needs to be promoted
Second Priority
  e) Maintain capacity for 'bottom-up' innovative funding
Third Priority
  c) Joint academic-industry funding models

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population  
   Agree
b) Improve education and training of healthcare professionals  
   Strongly Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers  
   Strongly Agree
d) Increase training for translational and clinician-scientists  
   Agree
e) Increase numbers of post-doctoral level researchers  
   Agree

Question 2: If you had to choose one priority from the points above what would it be?  
   b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”  
   Agree
b) Survey long-term care standards and provision across Europe  
   Strongly Agree
c) Research into the needs of carers  
   Strongly Agree
d) Research into care approaches including end of life decision-making  
   Strongly Agree
e) Rethink approaches to care  
   Strongly Agree
f) Understand and investigate influence of comorbidities  
   Strongly Agree
g) Conduct research into effects of nutrition and frailty  
   Agree
h) Determine cost-effectiveness of healthcare pathways  
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority  
   f) Understand and investigate influence of comorbidities on NDD
Second Priority  
   c) Research into the needs of carers
Third Priority  
   d) Research end of life decision making

Question 3: How would you define “care”?  
   Provision of whatever is needed to support an individual’s best possible quality of life - physical, mental, psychological, emotional.
Question 4: Have you any (additional) suggestions as to how care systems should be revised?  
  Provision of interim care for the relief of informal carers; best practice guidelines for care in hospitals both short and long term.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?  
  Need high quality training and on-going support for the informal carer in caring role and recognition of the impact of caring on the quality of life of the carer.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points  
a) Increase involvement of individuals in research  
  Agree  
b) Promote development of non-pharmacological interventions  
  Strongly Agree  
c) Conduct multi-centre primary prevention studies  
  Strongly Agree  
d) Ensure better patient selection/stratification  
  Strongly Agree  
e) Rethink approach to therapeutics  
  Strongly Agree  
f) Support for high-risk projects  
  Strongly Agree

Question 2: Please rank the suggestions in order of priority  
First Priority  
c) Conduct multi-centre primary prevention studies  
Second Priority  
d) Ensure better patient selection/stratification  
Third Priority  
f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?  
  Explicit information about the benefits of involvement in research. Campaigns. Discussion at different times and long before end of life when discussing brain material donation.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?  
  Diet, alcohol intake, exposure to illness in childhood and adolescence, lifestyle.

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points  
a) Understand relationship between neurodegenerative disease and ageing  
  Agree  
b) Improve understanding of disease stages  
  Agree  
c) Improve understanding of disease mechanisms  
  Strongly Agree  
d) Develop an improved understanding of the genetic basis for NDD  
  Strongly Agree  
e) Determine the importance of genetic and environmental risk factors  
  Strongly Agree  
f) Focus research on rare hereditary forms of disease  
  Strongly Agree  
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups  
  Strongly Agree  
h) Develop more representative animal and cell-based models of disease  
  Agree

Question 2: Please rank the suggestions in order of priority  
First Priority  
c) Improve understanding of disease mechanisms  
Second Priority  
e) Determine the importance of genetic and environmental risk factors  
Third Priority  
h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Not sure

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis
Agree
b) Redefine and harmonise clinical endpoints and outcomes
Strongly Agree
c) Develop new biomarkers
Strongly Agree
d) Consider regulatory approaches
Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
a) Improve access to, and sharing of, infrastructure and resources
Agree
b) Improve access to patient groups, samples and data
Strongly Agree
c) Improve data and sample collection
Agree
d) Develop a register of persons with cognitive impairment
Agree
e) Develop centres of excellence
Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
b) Improve access to patient groups, samples and data
Second Priority
d) Develop a register of persons with cognitive impairment
Third Priority
a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?
Set up a third-party or coalition to hold databank of research available to be accessed by others. Would require strong ethics, governance and rules of engagement. Researchers from industry and academia could register but not necessarily declare their involvement. Could be funded by charging for access.

Question 4: What are your views on making data open access? If you forsee difficulties, how can we overcome these?
Open access might defer contributions. There is a culture (of course) of competitiveness so perhaps allowing time to elapse before requiring data to become accessible. Tricky one.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
De-skilling of health care professionals etc. in non-specialist centres. Difficulties of access for patients.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
Agree
b) Ensure greater engagement with regulators
Agree
c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
Agree
d) Encourage industry to adopt a pre-competitive approach to research
Strongly Agree
e) Rethink patent lifetime and conduct public-private clinical trials
Agree
f) Review and update legislation on treatment  
   Strongly Agree  

g) Review and update legislation on privacy and data disclosure  
   Strongly Agree  

Question 2: Please rank the suggestions in order of priority  
   First Priority  
   Second Priority  
   Third Priority  

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

**Funding and funding mechanisms**

Question 1: Please indicate to what extent you endorse the following points  
   a) Translational research needs to be promoted  
   b) Encourage open-access sharing of data and materials  
   c) Joint academic-industry funding models  
   d) Simplify funding application systems  
   e) Maintain capacity for ‘bottom-up’ innovative funding  

Question 2: Please rank the suggestions in order of priority  
   First Priority  
   Second Priority  
   Third Priority  

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

**Concluding questions**

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)  
   Earlier and close involvement of patients and patient organisations in the early stages of clinical trial development - could be involved at the design stage.  

Question 2: Do you have any comments on how to implement the above suggestion(s)?  
   see models of patient involvement in HIV/AIDS research and OMERACT  

Question 3: Is there anything else you would like to tell us?
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   Strongly Agree
b) Improve education and training of healthcare professionals
   Strongly Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers
   Strongly Agree
d) Increase training for translational and clinician-scientists
   Strongly Agree
e) Increase numbers of post-doctoral level researchers
   Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?
   d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?
   Translational specialists; esp. the translation between basic -, clinical research and patients.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Agree
b) Survey long-term care standards and provision across Europe
   Agree
c) Research into the needs of carers
   Strongly Agree
d) Research into care approaches including end of life decision-making
   Agree
e) Rethink approaches to care
   Agree
f) Understand and investigate influence of comorbidities
   Agree
g) Conduct research into effects of nutrition and frailty
   Agree
h) Determine cost-effectiveness of healthcare pathways
   Agree

Question 2: Please rank the suggestions in order of priority
   First Priority
   c) Research into the needs of carers
   e) Rethink approaches to care
   h) Determine cost-effectiveness of healthcare pathways
   Second Priority
   d) Research into care approaches including end of life decision-making
   Third Priority

Question 3: How would you define “care”?
   Getting support in each stage of the disease for selfsupporting and to optimise Living conditions.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research
   Agree
b) Promote development of non-pharmacological interventions
   Neutral

c) Conduct multi-centre primary prevention studies
   Agree

d) Ensure better patient selection/stratification
   Strongly Agree

e) Rethink approach to therapeutics
   Agree

f) Support for high-risk projects
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   c) Conduct multi-centre primary prevention studies

Second Priority
   e) Rethink approach to therapeutics

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
Making more publicity.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
   Strongly Agree

b) Improve understanding of disease stages
   Agree

c) Improve understanding of disease mechanisms
   Agree

d) Develop an improved understanding of the genetic basis for NDD
   Agree

e) Determine the importance of genetic and environmental risk factors
   Agree

f) Focus research on rare hereditary forms of disease
   Strongly Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
   Agree

h) Develop more representative animal and cell-based models of disease
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   b) Improve understanding of disease stages

Second Priority
   a) Understand relationship between NDD and ageing

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
   c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis
   Agree

b) Redefine and harmonise clinical endpoints and outcomes
   Agree

c) Develop new biomarkers
   Strongly Agree

d) Consider regulatory approaches
   Agree
Question 2: Which of the following do you think is most important in terms of biomarkers?
   c) Providing an indicator of, and sensitivity to, disease progression

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
   a) Improve access to, and sharing of, infrastructure and resources
      Agree
   b) Improve access to patient groups, samples and data
      Agree
   c) Improve data and sample collection
      Agree
   d) Develop a register of persons with cognitive impairment
      Agree
   e) Develop centres of excellence
      Strongly Agree

Question 2: Please rank the suggestions in order of priority
   First Priority
      e) Develop centres of excellence
   Second Priority
      a) Improve access to, and sharing of, infrastructure and resources
   Third Priority

Question 3: What can be done to facilitate increased sharing of data?
   Emphasize the importance for the patients!

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
   a) Need for evidence-based policy
      Agree
   b) Ensure greater engagement with regulators
      Neutral
   c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
      Agree
   d) Encourage industry to adopt a pre-competitive approach to research
      Agree
   e) Rethink patent lifetime and conduct public-private clinical trials
      Agree
   f) Review and update legislation on treatment
      Agree
   g) Review and update legislation on privacy and data disclosure
      Agree

Question 2: Please rank the suggestions in order of priority
   First Priority
   Second Priority
   Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
   a) Translational research needs to be promoted
      Strongly Agree
   b) Encourage open-access sharing of data and materials
      Agree
   c) Joint academic-industry funding models
      Agree
   d) Simplify funding application systems
      Agree
   e) Maintain capacity for 'bottom-up' innovative funding
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority
   a) Translational research needs to be promoted

Second Priority
   e) Maintain capacity for 'bottom-up' innovative funding

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)
   Progress in research in rare diseases, like Hunntington Disease, might be leading to more knowledge in diseases like Alzheimer.

Question 2: Do you have any comments on how to implement the above suggestion(s)?
   Getting Research in HD as a guidance for studies in NDD; finance more in research in rare diseases.

Question 3: Is there anything else you would like to tell us?
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   Agree
b) Improve education and training of healthcare professionals
   Neutral
c) Increase numbers of neurodegenerative disease (NDD) researchers
   Neutral
d) Increase training for translational and clinician-scientists
   Agree
e) Increase numbers of post-doctoral level researchers
   Neutral

Question 2: If you had to choose one priority from the points above what would it be?
   d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Strongly Agree
b) Survey long-term care standards and provision across Europe
   Agree
c) Research into the needs of carers
   Agree
d) Research into care approaches including end of life decision-making
   Agree
e) Rethink approaches to care
   Agree
f) Understand and investigate influence of comorbidities
   Agree
g) Conduct research into effects of nutrition and frailty
   Agree
h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority
First Priority
   f) Understand and investigate influence of comorbidities on NDD
Second Priority
   c) Research into the needs of carers
Third Priority
   e) Rethink approaches to care

Question 3: How would you define “care”?  

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   Real patient-centered care. (More) communication between various caregivers (a.o. various medical specialists) that care for a patient.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research
   Neutral
b) Promote development of non-pharmacological interventions
   Agree
c) Conduct multi-centre primary prevention studies
   Agree
d) Ensure better patient selection/stratification
Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing  
   Neutral
b) Improve understanding of disease stages  
   Agree
c) Improve understanding of disease mechanisms  
   Agree
d) Develop an improved understanding of the genetic basis for NDD  
   Agree
e) Determine the importance of genetic and environmental risk factors  
   Agree
f) Focus research on rare hereditary forms of disease  
   Strongly Disagree
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups  
   Agree
h) Develop more representative animal and cell-based models of disease  
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority  
   h) Develop more representative animal and cell-based models
Second Priority  
   g) Establish pan-European population-based studies
Third Priority  
   b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable
   When there are no adequate animal models

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing  
   Neutral
b) Improve understanding of disease stages  
   Agree
c) Improve understanding of disease mechanisms  
   Agree
d) Develop an improved understanding of the genetic basis for NDD  
   Agree
e) Determine the importance of genetic and environmental risk factors  
   Agree
f) Focus research on rare hereditary forms of disease  
   Strongly Disagree
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups  
   Agree
h) Develop more representative animal and cell-based models of disease  
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority  
   h) Develop more representative animal and cell-based models
Second Priority  
   g) Establish pan-European population-based studies
Third Priority  
   b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable
   When there are no adequate animal models

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis  
   Strongly Agree
b) Redefine and harmonise clinical endpoints and outcomes  
   Strongly Agree
c) Develop new biomarkers  
   Agree
d) Consider regulatory approaches  
   Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?
**Data, registries, repositories and centres**

**Question 1: Please indicate to what extent you endorse the following points**

a) Improve access to, and sharing of, infrastructure and resources  
   - Agree

b) Improve access to patient groups, samples and data  
   - Agree

c) Improve data and sample collection  
   - Strongly Agree

d) Develop a register of persons with cognitive impairment  
   - Strongly Disagree

e) Develop centres of excellence  
   - Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**
- c) Improve data and sample collection

**Second Priority**
- b) Improve access to patient groups, samples and data
- e) Develop centres of excellence

**Third Priority**

**Question 3: What can be done to facilitate increased sharing of data?**
- harmonize and standardize techniques and measures / outcomes

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**
- yes, limited viability of/ room for viewpoints / hypotheses that are very different from the common hypotheses.

**Policy, regulation and legislation**

**Question 1: Please indicate to what extent you endorse the following points**

a) Need for evidence-based policy  
   - Agree

b) Ensure greater engagement with regulators  
   - Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community  
   - Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research  
   - Agree

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

**Question 2: Please rank the suggestions in order of priority**

First Priority
- Second Priority
- Third Priority

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

**Funding and funding mechanisms**

**Question 1: Please indicate to what extent you endorse the following points**

a) Translational research needs to be promoted  
   - Strongly Agree

b) Encourage open-access sharing of data and materials  
   - Strongly Agree

c) Joint academic-industry funding models  
   - Agree

d) Simplify funding application systems  
   - Agree

e) Maintain capacity for 'bottom-up' innovative funding  
   - Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

First Priority
- Second Priority
- Third Priority
Second Priority
   e) Maintain capacity for 'bottom-up' innovative funding
Third Priority
   b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   Agree
b) Improve education and training of healthcare professionals
   Strongly Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers
   Strongly Agree
d) Increase training for translational and clinician-scientists
   Agree
e) Increase numbers of post-doctoral level researchers
   Agree

Question 2: If you had to choose one priority from the points above what would it be?
   b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?
   An end of life protocol

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Agree
b) Survey long-term care standards and provision across Europe
   Neutral
c) Research into the needs of carers
   Strongly Agree
d) Research into care approaches including end of life decision-making
   Strongly Agree
e) Rethink approaches to care
   Agree
f) Understand and investigate influence of comorbidities
   Neutral
g) Conduct research into effects of nutrition and frailty
   Neutral
h) Determine cost-effectiveness of healthcare pathways
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   d) Research end of life decision making
Second Priority
   c) Research into the needs of carers
Third Priority
   f) Understand and investigate influence of comorbidities on NDD

Question 3: How would you define “care”?
   Providing services to people which enable them to live their lives as if they did not have their disability

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
I would suggest a menu of services available is provided including all facets of care such as healthcare, social services, volunteer groups, support groups, helplines etc.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Provide free at home unlimited 24/7 care if necessary

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research
   Neutral

b) Promote development of non-pharmacological interventions
   Neutral

c) Conduct multi-centre primary prevention studies
   Agree

d) Ensure better patient selection/stratification
   Neutral

e) Rethink approach to therapeutics
   Agree

f) Support for high-risk projects
   Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
   e) Rethink approach to therapeutics

Second Priority
   b) Promote development of non-pharmacological interventions

Third Priority
   a) Increase involvement of individuals in research

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
Marketing campaigns targetted via support groups

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing
   Neutral

b) Improve understanding of disease stages
   Neutral

c) Improve understanding of disease mechanisms
   Neutral

d) Develop an improved understanding of the genetic basis for NDD
   Agree

e) Determine the importance of genetic and environmental risk factors
   Agree

f) Focus research on rare hereditary forms of disease
   Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
   Neutral

h) Develop more representative animal and cell-based models of disease
   Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
   d) Develop an improved understanding of the genetic basis

Second Priority
   e) Determine the importance of genetic and environmental risk factors

Third Priority
   h) Develop more representative animal and cell-based models

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

**Diagnosis, disease definitions and outcome measures**

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis
b) Redefine and harmonise clinical endpoints and outcomes
c) Develop new biomarkers
d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

**Data, registries, repositories and centres**

Question 1: Please indicate to what extent you endorse the following points
a) Improve access to, and sharing of, infrastructure and resources
b) Improve access to patient groups, samples and data
c) Improve data and sample collection
d) Develop a register of persons with cognitive impairment
 Agree

e) Develop centres of excellence
 Agree

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

**Policy, regulation and legislation**

Question 1: Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
b) Ensure greater engagement with regulators
c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
d) Encourage industry to adopt a pre-competitive approach to research
e) Rethink patent lifetime and conduct public-private clinical trials
f) Review and update legislation on treatment
g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

**Funding and funding mechanisms**

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
b) Encourage open-access sharing of data and materials
c) Joint academic-industry funding models
d) Simplify funding application systems
e) Maintain capacity for ‘bottom-up’ innovative funding

Question 2: Please rank the suggestions in order of priority
First Priority
Second Priority
Third Priority
Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
**Education, training and collaboration**

**Question 1:** Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population  
   Agree

b) Improve education and training of healthcare professionals  
   Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers  
   Strongly Agree

d) Increase training for translational and clinician-scientists  
   Agree

e) Increase numbers of post-doctoral level researchers  
   Agree

**Question 2:** If you had to choose one priority from the points above what would it be?  
   b) Improve education and training of healthcare professionals

**Question 3:** Are there any other specialist areas which you think need promoting or should be given greater emphasis?

**Health and social care issues**

**Question 1:** Please indicate to what extent you endorse the following points

a) Define the term “care”  
   Agree

b) Survey long-term care standards and provision across Europe  
   Agree

c) Research into the needs of carers  
   Strongly Agree

d) Research into care approaches including end of life decision-making  
   Strongly Agree

e) Rethink approaches to care  
   Agree

f) Understand and investigate influence of comorbidities  
   Agree

g) Conduct research into effects of nutrition and frailty  
   Strongly Agree

h) Determine cost-effectiveness of healthcare pathways  
   Agree

**Question 2:** Please rank the suggestions in order of priority

**First Priority**

   c) Research into the needs of carers

**Second Priority**

   d) Research end of life decision making

**Third Priority**

   b) Survey long-term care standards and provision across Europe

**Question 3:** How would you define “care”?

**Question 4:** Have you any (additional) suggestions as to how care systems should be revised?

**Question 5:** Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

**Prevention/treatment strategies and trials**

**Question 1:** Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research  
   Strongly Agree

b) Promote development of non-pharmacological interventions  
   Neutral
c) Conduct multi-centre primary prevention studies  
   Agree

d) Ensure better patient selection/stratification  
   Neutral

e) Rethink approach to therapeutics  
   Neutral

f) Support for high-risk projects  
   Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Increase involvement of individuals in research
Second Priority
   c) Conduct multi-centre primary prevention studies
Third Priority
   d) Ensure better patient selection/stratification

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing  
   Agree

b) Improve understanding of disease stages  
   Strongly Agree

c) Improve understanding of disease mechanisms  
   Agree

d) Develop an improved understanding of the genetic basis for NDD  
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   b) Improve understanding of disease stages
Second Priority
   c) Improve understanding of disease mechanisms
Third Priority
   e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
   c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis  
   Agree

b) Redefine and harmonise clinical endpoints and outcomes  
   Neutral

c) Develop new biomarkers  
   Agree

d) Consider regulatory approaches  
   Neutral
Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources
   Strongly Agree

b) Improve access to patient groups, samples and data
   Agree

c) Improve data and sample collection
   Strongly Agree

d) Develop a register of persons with cognitive impairment
   Agree

e) Develop centres of excellence
   Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
   a) Improve access to, and sharing of, infrastructure and resources

Second Priority
   c) Improve data and sample collection

Third Priority
   b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you forsee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy
   Agree

b) Ensure greater engagement with regulators
   Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
   Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research
   Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials
   Agree

f) Review and update legislation on treatment
   Strongly Agree

g) Review and update legislation on privacy and data disclosure
   Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
   c) Facilitate research in areas outside university and hospital sectors

Second Priority
   d) Encourage industry to adopt pre-competitive approach

Third Priority
   a) Need for evidence-based policy

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted
   Neutral

b) Encourage open-access sharing of data and materials
   Neutral

c) Joint academic-industry funding models
   Neutral
d) Simplify funding application systems
   Agree

e) Maintain capacity for 'bottom-up' innovative funding
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   d) Simplify funding application systems
Second Priority
   e) Maintain capacity for 'bottom-up' innovative funding
Third Priority
   b) Encourage open-access sharing of data and materials

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?
Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points
a) Improve dialogue between researchers and the wider population
   *Strongly Agree*

b) Improve education and training of healthcare professionals
   *Strongly Agree*

c) Increase numbers of neurodegenerative disease (NDD) researchers
   *Strongly Agree*

d) Increase training for translational and clinician-scientists
   *Strongly Agree*

e) Increase numbers of post-doctoral level researchers
   *Strongly Agree*

Question 2: If you had to choose one priority from the points above what would it be?
   *d) Increase training for translational and clinician-scientists*

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   *Neutral*

b) Survey long-term care standards and provision across Europe
   *Agree*

c) Research into the needs of carers
   *Strongly Agree*

d) Research into care approaches including end of life decision-making
   *Strongly Agree*

e) Rethink approaches to care
   *Strongly Agree*

f) Understand and investigate influence of comorbidities
   *Strongly Agree*

g) Conduct research into effects of nutrition and frailty
   *Strongly Agree*

h) Determine cost-effectiveness of healthcare pathways
   *Agree*

Question 2: Please rank the suggestions in order of priority
   First Priority
   Second Priority
   Third Priority

Question 3: How would you define “care”?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research
   *Strongly Agree*

b) Promote development of non-pharmacological interventions
   *Agree*

c) Conduct multi-centre primary prevention studies
   *Strongly Agree*
d) Ensure better patient selection/stratification
   Agree

e) Rethink approach to therapeutics
   Strongly Agree

f) Support for high-risk projects
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
a) Increase involvement of individuals in research

Second Priority
e) Rethink approach to therapeutics

Third Priority
f) Support for high-risk projects

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
   Provide relevant and comprehensive information in lay language, and at the same time explaining why the help of patients is essential for meaningful research.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
   Strongly Agree

b) Improve understanding of disease stages
   Strongly Agree

b) Improve understanding of disease stages
   Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD
   Strongly Agree

e) Determine the importance of genetic and environmental risk factors
   Strongly Agree

f) Focus research on rare hereditary forms of disease
   Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
   Strongly Agree

h) Develop more representative animal and cell-based models of disease
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
c) Improve understanding of disease mechanisms

Second Priority
h) Develop more representative animal and cell-based models

Third Priority
e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable
   At this moment I don't think there is enough justification to exclude the step of animal models. Most cell-based models are not representative and predictive enough for risks and effects in humans.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points
a) Redefine and standardise disease definitions and diagnosis
   Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes
   Strongly Agree

c) Develop new biomarkers
   Strongly Agree

d) Consider regulatory approaches
Question 2: Which of the following do you think is most important in terms of biomarkers?
   a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points
   a) Improve access to, and sharing of, infrastructure and resources
      Strongly Agree
   b) Improve access to patient groups, samples and data
      Strongly Agree
   c) Improve data and sample collection
      Strongly Agree
   d) Develop a register of persons with cognitive impairment
      Strongly Agree
   e) Develop centres of excellence
      Strongly Agree

Question 2: Please rank the suggestions in order of priority
   First Priority
       e) Develop centres of excellence
   Second Priority
       b) Improve access to patient groups, samples and data
   Third Priority
       a) Improve access to, and sharing of, infrastructure and resources

Question 3: What can be done to facilitate increased sharing of data?
   Increase openness, confidence and trust between the research groups.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   I am aware of the benefits of open access data, but we deal with privacy-related information/data. Therefore, data sharing should be traceable and in collaboration with the group who has collected the data.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   We have to be aware of the risks of becoming too harmonious in thinking and acting and that research lines in 1 NDD may be influenced by the local policy.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
   a) Need for evidence-based policy
      Agree
   b) Ensure greater engagement with regulators
      Strongly Agree
   c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
      Agree
   d) Encourage industry to adopt a pre-competitive approach to research
      Agree
   e) Rethink patent lifetime and conduct public-private clinical trials
      Strongly Agree
   f) Review and update legislation on treatment
      Strongly Agree
   g) Review and update legislation on privacy and data disclosure
      Strongly Agree

Question 2: Please rank the suggestions in order of priority
   First Priority
       e) Rethink patent lifetime and conduct public-private clinical trials
   Second Priority
       b) Ensure greater engagement with regulators
   Third Priority
       g) Review and update legislation on privacy and data disclosure

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms
Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
   Strongly Agree
b) Encourage open-access sharing of data and materials
   Neutral
c) Joint academic-industry funding models
   Strongly Agree
d) Simplify funding application systems
   Strongly Agree
e) Maintain capacity for 'bottom-up' innovative funding
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Translational research needs to be promoted
Second Priority
   c) Joint academic-industry funding models
Third Priority
   e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?