### Directory of healthcare professional respondees

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#### Anonymous responses from organisations/institutions

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#### Responses from individuals

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<td>Koen</td>
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<td>Elizabeth</td>
<td>Coulthard</td>
<td>Neurology Consultant</td>
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<td>Dr</td>
<td>Nenad</td>
<td>Bogdanovic</td>
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<td>Dr</td>
<td>Ales</td>
<td>Kogoj</td>
<td>Psychiatrist</td>
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<td>Lynch</td>
<td>Consultant Neurologist</td>
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<td>Dr</td>
<td>Charlotte</td>
<td>Morgan</td>
<td>General Practitioner</td>
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### Anonymous responses from individuals

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An additional 5 responses were received from individuals who 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
   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
   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”
   Neutral
b) Survey long-term care standards and provision across Europe
   Neutral
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
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   h) Determine cost-effectiveness of healthcare pathways
Second Priority
   f) Understand and investigate influence of comorbidities on NDD
Third Priority
   c) Research into the needs of carers

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
   Agree
b) Promote development of non-pharmacological interventions
   Strongly 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
e) Rethink approach to therapeutics
Second Priority
c) Conduct multi-centre primary prevention studies
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?

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
   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
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
c) Improve understanding of disease mechanisms
Second Priority
d) Develop an improved understanding of the genetic basis
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?
b) Neuronal inflammation

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
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
   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
   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?

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
   Strongly 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
   Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Need for evidence-based policy
Second Priority
   b) Ensure greater engagement with regulators
Third Priority
   f) Review and update legislation on treatment

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  
      Strongly Agree
   c) Joint academic-industry funding models  
      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  
      b) Encourage open-access sharing of data and materials
   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?
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
   - Agree
d) Increase training for translational and clinician-scientists
   - Agree
e) Increase numbers of post-doctoral level researchers
   - Agree
f) Define the term “care”
   - Neutral
g) Survey long-term care standards and provision across Europe
   - Strongly Agree
h) Research into the needs of carers
   - Agree
i) Research into care approaches including end of life decision-making
   - Agree
j) Rethink approaches to care
   - Agree
k) Understand and investigate influence of comorbidities
   - Agree
l) Conduct research into effects of nutrition and frailty
   - Agree
m) 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
   - d) Research end of life decision making
Third Priority
   - e) Rethink approaches to care

Question 3: How would you define “care”?
   - assist as wished by the client in an highly ethical way

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   - large long term care facilities are past, historical institutions of no added value for people with dementia
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  
   - 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?

   - promote living will in all countries  

**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?

   - multilinguism, creativity as prevention  

**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  
   - Strongly Agree  

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

f) Focus research on rare hereditary forms of disease  
   - Disagree  

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  
   - Neutral  

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

**First Priority**
   - g) Establish pan-European population-based studies  

**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?

   - d) The biological basis of behavioural and psychological symptoms
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 idea

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
   Neutral
d) Consider regulatory approaches
   Neutral

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
   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
   d) Develop a register of persons with cognitive impairment
Third Priority

Question 3: What can be done to facilitate increased sharing of data?
   work with data  existing in our  country but  no  researchers paid  to  work on them !!!

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   more  a legal aspect  which i  cannot  answer

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

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

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
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Translational research needs to be promoted
Second Priority
   b) Encourage open-access sharing of data and materials
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?
   nearly no offer for research in this field in luxembourg!!!
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
   Agree
d) Increase training for translational and clinician-scientists
   Strongly 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?
   Accessible statistics both in terms of actual access to statisticians and enabling clinicians to understand statistics, training for the ignorant interested.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Disagree
b) Survey long-term care standards and provision across Europe
   Strongly 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
   Disagree
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
   b) Survey long-term care standards and provision across Europe
Second Priority
   g) Conduct research into effects of nutrition and frailty
Third Priority

Question 3: How would you define “care”?
   An umbrella term to describe a designer approach to each individual in order to nurture a human being physically, intellectually and emotional - where nurturing means enabling a person to reach their potential at any given time or stage in their lives. Care will therefore need to include others.
Question 4: Have you any (additional) suggestions as to how care systems should be revised? 
Compassionately.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages? 
More flexibility and initiative to be encourage in health care workers - less emphasis on tick boxes and time restraints where-ever possible.

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
   Strongly Agree
d) Ensure better patient selection/stratification
   Disagree
e) Rethink approach to therapeutics
   Agree
f) Support for high-risk projects
   Disagree

Question 2: Please rank the suggestions in order of priority
First Priority
   c) Conduct multi-centre primary prevention studies
Second 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?
Promote the current ways of working that are a result of individuals in the past taking part in 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?
Prevention of delirium - mobilisation programme for the patients at risk, cognition programme.

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
   Disagree
b) Improve understanding of disease stages
   Neutral
c) Improve understanding of disease mechanisms
   Agree
d) Develop an improved understanding of the genetic basis for NDD
   Neutral
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
   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?
   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
   Strongly Agree
c) Develop new biomarkers
   Neutral
d) Consider regulatory approaches
   Disagree

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
   Neutral
c) Improve data and sample collection
   Agree
d) Develop a register of persons with cognitive impairment
   Strongly Disagree
e) Develop centres of excellence
   Disagree

Question 2: Please rank the suggestions in order of priority
First Priority
   c) Improve data and sample collection
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?

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?
   Withdrawal of resources and expertise from institutions which likely have access to large heterogeneous patient population for study opportunites. Competition within centre of excellence for individual patients to participate in the different trials.

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?
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?
   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?

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
   Strongly 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
   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
   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
   c) Research into the needs of carers

Question 3: How would you define “care”?
   Care should encompass a range of requirements based on the needs of the individual concerned. Care can range from meeting all an individuals personal and social needs to enabling someone to meet those needs for themselves

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

Ensure that the individuals concerned are fully involved in deciding the priorities of changing any balance of care, so that this change is driven by their needs rather than the needs and cost of the service provider.

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
   b) Promote development of non-pharmacological interventions

Second Priority
   a) Increase involvement of individuals in research

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?

Wider publicity / use of national disease specific support agencies / charities

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
   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
   Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
   a) Understand relationship between NDD and ageing

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

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
   Neutral
b) Improve access to patient groups, samples and data
   Neutral
c) Improve data and sample collection
   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
Second Priority
Third Priority

Problem, 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
   Strongly Agree
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)
   The most effective physical / rehabilitation approaches to use with people with NDD

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
   Neutral
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?
   Elderly with comorbidity. Due to the possibility of pharmaceutical treatment of some neurodegenerative diseases geriatric research is focused - at least in Sweden - very much on neurodegenerative disorders.

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”?
   The overall care of a person in need of help in some way

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
More focus on quality of life in terms of feeling of safety, possibility to social contacts, having a meaningful time, individualised care.

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

More support and education to the relatives in the way they want it in case they are the 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
   Neutral
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
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   d) Ensure better patient selection/stratification
Second Priority
   b) Promote development of non-pharmacological interventions
Third Priority
   e) Rethink approach to therapeutics

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
   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
   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
   Neutral

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
   Agree

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
   Agree

e) Develop centres of excellence
   Agree

Question 2: Please rank the suggestions in order of priority

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

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
   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
   Agree

f) Review and update legislation on treatment
   Agree

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

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
   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
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   d) Simplify funding application systems
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?
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?
   Neurology, Psychiatry, Neuroscience

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
   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
Second Priority
Third Priority

Question 3: How would you define “care”?
   Resolve and meet the needs of patients in social, psychological and health especially, in a quiet and safe environment closely with the family and main caregiver

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?
Need to increase care professionals, health and social services, to serve the best for the patient at home or on the first level of care.

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

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?

We seem to have more regard to the personal interest of researchers or organizations that interest or benefit to the patient.

**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
   - 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
   - a) Understand relationship between NDD and ageing

Second Priority
   - c) Improve understanding of disease mechanisms

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.
Probably the cell cultures (neurons and fibroblasts) and HeLa cells to better understand the processes of degeneration toward aging or from cancer, because of the possibility of being antagonistic phenomena but with the same cellular basis.

**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
   - Strongly 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
   - 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**

**Third Priority**

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

Possibly the most complicated, plus some share their data, while others use their own benefit

**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?

Although it may bring together the best researchers in each field, many just looking at the navel themselves and sometimes they think they are the only ones in possession of absolute truth associated with the disease

**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
   - Strongly 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**

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

Possibly the most complicated, plus some share their data, while others use their own benefit

**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?

Although it may bring together the best researchers in each field, many just looking at the navel themselves and sometimes they think they are the only ones in possession of absolute truth associated with the disease
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  
      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  
      Agree

**Question 2:** Please rank the suggestions in order of priority  
   **First Priority**  
   a) Translational research needs to be promoted  
   **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
   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
f) Define the term “care”
   Neutral
g) Survey long-term care standards and provision across Europe
   Agree
h) Research into the needs of carers
   Agree
i) Research into care approaches including end of life decision-making
   Agree
j) Rethink approaches to care
   Agree
k) Understand and investigate influence of comorbidities
   Agree
l) Conduct research into effects of nutrition and frailty
   Agree
m) Determine cost-effectiveness of healthcare pathways
   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
   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
   b) Survey long-term care standards and provision across Europe
Second Priority
   f) Understand and investigate influence of comorbidities on NDD
Third Priority
   g) Conduct research into effects of nutrition and frailty

Question 3: How would you define “care”?
   Strength lives capable of surrounding, of supporting and of helping

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
      Agree
   d) Ensure better patient selection/stratification
      Strongly Agree
   e) Rethink approach to therapeutics
      Strongly Agree
   f) Support for high-risk projects
      Neutral

Question 2: Please rank the suggestions in order of priority
   First Priority
      d) Ensure better patient selection/stratification
   Second Priority
      e) Rethink approach to therapeutics
   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?
   The first step is to promote such research to the medical doctors (they are often afraid to propose such research). More information to this population is of importance. The second step is to include the associations of patients and caregivers that can help to promote such research. The third steps could be advertisings for general 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?
   Air pollution   Water pollution   Radioactivity?   Rare and frequent infections

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
      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
      Neutral

Question 2: Please rank the suggestions in order of priority
   First Priority
      a) Understand relationship between NDD and ageing
   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?
   b) Neuronal inflammation
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?
   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
   Agree
d) Develop a register of persons with cognitive impairment
   Strongly Agree
e) Develop centres of excellence
   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
   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?
   Open access is a necessity +++.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   The existence of few centres of excellence (for example one or two in each countries) can diminished the global performance of the system because there is also a need of proximity with the patients. A centre of excellence with a specificity in each european region of 5 million of inhabitants could be a solution.

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
   Agree
f) Review and update legislation on treatment
   Agree
g) Review and update legislation on privacy and data disclosure
Question 2: Please rank the suggestions in order of priority
First Priority
   a) Need for evidence-based policy
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  
   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
   a) Translational research needs to be promoted
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
      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
      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?
   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
      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
      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
   Third Priority
      a) Define the term "care"

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
   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
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   c) Conduct multi-centre primary prevention studies
Second Priority
   b) Promote development of non-pharmacological interventions
Third Priority
   e) Rethink approach to therapeutics

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
   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
   Strongly 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
   c) Improve understanding of disease mechanisms
Second Priority
   g) Establish pan-European population-based studies
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  
   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?  
   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  
      Agree

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
   d) Develop a register of persons with cognitive impairment

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  
      Strongly 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  
      Strongly 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
   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
   Agree
c) Joint academic-industry funding models
   Agree
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
   b) Encourage open-access sharing of data and materials
Second Priority
   c) Joint academic-industry funding models
Third Priority
   a) Translational research needs to be promoted

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
   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?
   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?
   Psychosocial interventions

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
   Agree
d) Research into care approaches including end of life decision-making
   Neutral
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
   b) Survey long-term care standards and provision across Europe
Second Priority
   a) Define the term ‘care’
Third Priority
   d) Research end of life decision making

Question 3: How would you define “care”?
   As a global process that involves every dimension of person

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

Question 2: Please rank the suggestions in order of priority
   First Priority  
      b) Promote development of non-pharmacological interventions
   Second Priority  
      d) Ensure better patient selection/stratification
   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?
   I don't know

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?
   Quality of life, well-being

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

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  
      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?
   d) The biological basis of behavioural and psychological symptoms

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
   Neutral
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
   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
   b) Improve access to patient groups, samples and data
Third Priority
   d) Develop a register of persons with cognitive impairment

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

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

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

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
   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
   g) Review and update legislation on privacy and data disclosure
Second Priority
Question 2: Please rank the suggestions in order of priority
First Priority
  d) Simplify funding application systems
Second Priority
  b) Encourage open-access sharing of data and materials
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)
  Comunication and partecipation

Question 2: Do you have any comments on how to implement the above suggestion(s)?
  Partecipation and inclusion in research of public health system

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?
- The efficacy of psychosocial therapies in comparison with medication

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

Second Priority
- c) Research into the needs of carers
- e) Rethink approaches to care

Third Priority
- f) Understand and investigate influence of comorbidities

Question 3: How would you define “care”?
- Care is the complete support on the physical, mental and social domains of diseases or handicaps and 'Care' includes diagnosis, cure, therapy, assisted living, palliation.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
Care systems should overview the total content of disease specific pathways (including symptoms, diagnostic strategies, treatment, homecare, adapting to disabilities, palliation) Integration in care pathways

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Organising good coordination of care at home by specialist nurses who can overview the complete pathway and have multidisciplinary backup from specialists.

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
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   b) Promote development of non-pharmacological interventions

Second Priority
   e) Rethink approach to therapeutics

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?
   Give more information on how this could help their families to "be better off" in the future.

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 we're not yet in that position

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
   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
   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?
   d) The biological basis of behavioural and psychological symptoms
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
   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
   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
   d) Develop a register of persons with cognitive impairment

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?
There are pro's and con's to this proposal. Personal data need regulation and the more open, the data base is, the more regulation you need. For me as doctor the data are open enough.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
There are always risks, but to my opinion the advantages can be bigger, depending how these centres work. One thing that bothers me is the accessibility of these centres for patients living in remote areas. Another risk may be that local health care professionals feel less responsible because the patient is seen by the centre of excellence.

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
   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
   Neutral
e) Rethink patent lifetime and conduct public-private clinical trials
   Agree
f) Review and update legislation on treatment
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
      Strongly Agree
   b) Encourage open-access sharing of data and materials
      Agree
   c) Joint academic-industry funding models
      Disagree
   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
   a) Translational research needs to be promoted
Second Priority
   c) Joint academic-industry funding models
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)
   Promote interacting with lay organisation to improve efficacy and need-based research

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
   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?
   no

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Disagree
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
   c) Research into the needs of carers
Second Priority
   f) Understand and investigate influence of comorbidities on NDD
Third Priority
   h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define “care”?

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?

**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
   - Agree

f) Support for high-risk projects
   - Agree

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
- 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
   - 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
- g) Establish pan-European population-based studies

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  
   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?

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

Second Priority
   e) Develop centres of excellence

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?

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  
   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
   c) Facilitate research in areas outside university and hospital sectors

Second Priority
   f) Review and update legislation on treatment

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

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
   Agree
c) Joint academic-industry funding models
   Agree
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
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

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
   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?
   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
   Neutral
g) Conduct research into effects of nutrition and frailty
   Neutral
h) Determine cost-effectiveness of healthcare pathways
   Neutral

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
   e) Rethink approaches to care

Question 3: How would you define “care”?
   provision of support, including physical, medical, emotional and psychological to an individual from one or a
   team of people to improve the quality of their life and support their ongoing independence.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   need to take age into account. huge difference between the majority population - over 80, typical AD patient
   and the young onset patient witha familial disorder, whethr it be AD or MND-FTD

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
   Neutral

d) Ensure better patient selection/stratification
   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
   a) Increase involvement of individuals in research
Second Priority
   c) Conduct multi-centre primary prevention studies
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?
   make it a normal part of the culture of a clinic appointment to discuss research and to discuss brain 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?

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
   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
   Agree

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
   Agree

b) Redefine and harmonise clinical endpoints and outcomes
Agree
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
   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
      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?
   reduce competition and incentivise collaboration by sharing activity based funding and research kudos

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

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   disenfranchising smaller groups and funnelling clinical care into those COE only will de-skill others

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)

no

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

promotion via dendron and formation of cross disease groups and speciliast interest groups of clinicians and researchers. eg association of british neurologists development of special interest groups in these areas should be used to promote research improvement.

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?
   Improve and formalize joint working between gerontology/geriatric medicine/gerontological nursing and dementia research programmes 
   More emphasis on evidence-based management

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
   Neutral
d) Research into care approaches including end of life decision-making
   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
   b) Survey long-term care standards and provision across Europe
Second Priority
   f) Understand and investigate influence of comorbidities on NDD
Third Priority
   e) Rethink approaches to care

Question 3: How would you define “care”?  
   The application of the biopsychosocial model to assess need, and provide therapeutic, rehabilitative and support measures to maintain quality of life and health of the person affected by the neurological disease and those providing informal support

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
Universal application of key gerontological competence provides the substrate for better care of those with neurodegenerative illnesses

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
   Agreed definition of assessment, gerontological attuning of health-care system, rights-based approach prioritizing the needs and wish of the person affected

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
   Disagree
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
   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?
   Better training of healthcare staff, better public diffusion of benefits of 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?
   Lifestyle - exercise, blood pressure, smoking

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

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
   Agree
d) Consider regulatory approaches
   Strongly Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?
d) Facilitating back-translation to models of disease

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
   Neutral

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?
   Common clinical database, anonymized

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   Positive, data protection and security key issues

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   Tends to institutionalize and sclerose existing relationships, losing flexibility and access to a wider range of talent. Suggest networks of excellence

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
   Strongly 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
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
- 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?

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
  - Strongly Agree
- c) Joint academic-industry funding models
  - 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
- b) Encourage open-access sharing of data and materials

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

Third Priority
- d) Simplify funding application systems

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)
- Closer engagement, and incentivization, between social, clinical and laboratory academics
- Closer engagement with gerontology/geriatric medicine

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
      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
      Strongly Agree

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

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?
   Treatment and Management of Delirium in general hospital

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
      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
      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
   h) Determine cost-effectiveness of healthcare pathways

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
   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
   Agree

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
   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
   d) Develop an improved understanding of the genetic basis
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?
   d) The biological basis of behavioural and psychological symptoms

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?
   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
   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
      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
      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
      Agree
   b) Encourage open-access sharing of data and materials
      Agree
   c) Joint academic-industry funding models
      Agree
   d) Simplify funding application systems
e) Maintain capacity for 'bottom-up' innovative funding  
Strongly Agree

Question 2: Please rank the suggestions in order of priority  
First Priority  
   d) Simplify funding application systems  
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
   d) Increase training for translational and clinician-scientists
   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
   Neutral
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
   Neutral
h) Determine cost-effectiveness of healthcare pathways
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   b) Survey long-term care standards and provision across Europe

Second Priority
   h) Determine cost-effectiveness of healthcare pathways

Third Priority
   f) Understand and investigate influence of comorbidities on NDD

Question 3: How would you define “care”?
   Support on a medical, social and psychological basis.

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
   Neutral
f) Support for high-risk projects
   Agree

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
   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?
   - media campaigns illustrating the developments in diagnosis and therapeutic trials that are conducted and demonstrate the advances but also need for much further study

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?
   - effect of antihypertensives, anti-inflammatory agents on disease prevention - large prospective Database of normal ageing and risk parameters

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
   Strongly Agree
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
   Strongly 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
   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?
   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
   Yes. Imaging of biomarkers and their development, concerning targets that can be defined on the cellular level (eg amyloid, tau, alphasynuclein...), and where animal models are not very predictive for human findings.
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?
   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
   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
   b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?
   obligatory registration and database entry of ongoing trials

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   dependent on financial investments put into these. inclusion of pharmaceutical industry?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   sufficient and critical appraisal and evaluation of performance

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
   Disagree
d) Encourage industry to adopt a pre-competitive approach to research
   Disagree
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
   f) Review and update legislation on treatment
Second Priority
   g) Review and update legislation on privacy and data disclosure
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
    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
  d) Simplify funding application systems
Second Priority
  c) Joint academic-industry funding models
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
  Europe funded studies should be obliged to make data available upon completion of project to European centres.

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?
Dr Georgios SPATHARAKIS
Category of respondee: Healthcare professional - Primary Health Care
Country: Greece

**Education, training and collaboration**

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

<table>
<thead>
<tr>
<th>Point</th>
<th>Endorsement</th>
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<tbody>
<tr>
<td>a) Improve dialogue between researchers and the wider population</td>
<td>Agree</td>
</tr>
<tr>
<td>b) Improve education and training of healthcare professionals</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>c) Increase numbers of neurodegenerative disease (NDD) researchers</td>
<td>Agree</td>
</tr>
<tr>
<td>d) Increase training for translational and clinician-scientists</td>
<td>Strongly Agree</td>
</tr>
<tr>
<td>e) Increase numbers of post-doctoral level researchers</td>
<td>Agree</td>
</tr>
</tbody>
</table>

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

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

Question 2: Please rank the suggestions in order of priority

First Priority
- e) Rethink approaches to care

Second Priority
- a) Define the term ‘care’

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

Question 3: How would you define “care”?

Physical presence, interest in helping, human approach, holistic approach, respect of life, decision making, use of specialized technical support and/or skills, home adaptation, maintenance of social life, spirituality, medical 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?
- Training of more professionals
- Support from networks (for example, Alzheimer's Societies)
- Training of professional home carers
- Training and psychological support of informal, family carers
- Availability and low-cost, easy to use

**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
   e) Rethink approach to therapeutics
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?
- Information of general public
- Specific Information of family carers
- Get agreement and Support from local churches

**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
   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
   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
   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?
   d) The biological basis of behavioural and psychological symptoms
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
   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
   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
   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
   c) Improve data and sample collection
Third Priority
   d) Develop a register of persons with cognitive impairment

Question 3: What can be done to facilitate increased sharing of data?
   - Create permissive legislation but also ensure prevention of misuse
   - Create data bases
   - Specify the profile of those who will have access

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   - Data should be available on those working on the field, researchers of health professionals

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

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
  c) Joint academic-industry funding models
Second Priority
  d) Simplify funding application systems
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
   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?
   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
   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
   Neutral
h) Determine cost-effectiveness of healthcare pathways
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   e) Rethink approaches to care
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
   Agree

b) Promote development of non-pharmacological interventions
   Agree

c) Conduct multi-centre primary prevention studies
   Agree

d) Ensure better patient selection/stratification
   Strongly Agree

e) Rethink approach to therapeutics
   Strongly Agree

f) Support for high-risk projects
   Disagree

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?

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
   Neutral

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
   Agree

f) Focus research on rare hereditary forms of disease
   Disagree

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
   g) Establish pan-European population-based studies

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?
   d) The biological basis of behavioural and psychological symptoms

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
Neutral

d) Consider regulatory approaches
Neutral

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
   Neutral

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
  c) Improve data and sample collection
Third Priority
  e) Develop centres of excellence

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
   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
   Strongly 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
  c) Facilitate research in areas outside university and hospital sectors
Second Priority
  a) Need for evidence-based policy
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
   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
   c) Joint academic-industry funding models

Third Priority
   d) Simplify funding application systems

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  
   - **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”  
   - **Disagree**

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

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

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

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

- Care is not only given to NDD patients but also is the quality of life and stress of NDD carers. Long term diseases affect deeply carers and their exhaustion after many years of care affects the quality of the care provided, hence CARE is a wider concept.

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

- Health authorities do not measure effectively the cost effectiveness of CARE systems that affect NDD. More emphasis on the cost of the CARER should be done.
Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

More economic help for care at home is needed, family and friends cannot cope with a patient for years, hence economic help to alleviate the burden of 24h care of a patient is needed.

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
   Strongly Agree
d) Ensure better patient selection/stratification
   Strongly Agree
e) Rethink approach to therapeutics
   Strongly Agree
f) Support for high-risk projects
   Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
d) Ensure better patient selection/stratification
Second Priority
c) Conduct multi-centre primary prevention studies
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?
   Patients' associations should liaise more between health centres and patients and be more visible in the general society.

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?
   Patient stratification accordingly to their genetic and social background should be emphasized.

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
   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
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
g) Establish pan-European population-based studies
Second Priority
b) Improve understanding of disease stages
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?
   b) Neuronal inflammation
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.

There is no justification for missing out 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**
  - 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?

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

- **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?

- Greater funding for a pan European Network of Excellence that amalgates the most relevant stakeholders (primary care centres associations, hospitals, Universities)

**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**
  - Strongly 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**
c) Facilitate research in areas outside university and hospital sectors

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

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

**Second Priority**
- a) Translational research needs to be promoted

**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)?

  Promotion of a pan-European well funded agency that works in a coordinated homogenous manner to tackle homogenously NDD. For instance JPND is doing a great job promoting research calls, but every country is funding the calls in a heterogenous inefficient way. Good researchers in some countries received less fund than other researchers in the same Consortium but in other countries because each funding agency locates funds in a different way. A common fund where all Consortia compete should be encouraged.

**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
   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?
   integration and facilitation of research and health care practice (eg modifying barriers such as restrictive data protection regulations)

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
   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
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   h) Determine cost-effectiveness of healthcare pathways
Second Priority
   f) Understand and investigate influence of comorbidities on NDD
Third Priority
   c) Research into the needs of carers

Question 3: How would you define “care”?
   interventions designed to reverse or mitigate the effects of ill-health, substitute for activity limitations, or provide support for patients or their carers

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
'vertical integration' of health and social care: we need to remove barriers between organisations and providers, and design flexible pathways that include a variety of needs (including ensuring proper access to acute hospital and long term nursing care where this is appropriate and necessary)

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Two aspects, entitlement and decision making  
1. ensuring that rigorous assessment of needs has equal prominence to cost (the most intensive home care is more costly than institutional care)  
2. through a proper decision making process, such as is set out in the English mental capacity Act 2005

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  
   Disagree  
e) Rethink approach to therapeutics  
   Agree  
f) Support for high-risk projects  
   Strongly 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  
   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?
   better integration (or mandating) of research in health care practice

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 answered disagree to section C) because I do not believe we are in a position to conduct sensible primary prevention research (given that cardiovascular risk factor prevention is already established and uncontentious). We need more basic epidemiology first. There are options for mitigating effects - 'tertiary prevention'

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  
   Agree  
e) Determine the importance of genetic and environmental risk factors  
   Strongly Agree  
f) Focus research on rare hereditary forms of disease  
   Disagree  
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  
   g) Establish pan-European population-based studies
Second Priority  
   e) Determine the importance of genetic and environmental risk factors
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?
   d) The biological basis of behavioural and psychological symptoms

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
   probably not, given the need for satisfactory toxicology data (which would necessarily involve animals). However, in theory yes when it comes to assessing efficacy (given relative lack of good animal models): judge each case on its merits, and use patient and public involvement mechanisms to ensure probity.

**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
   Agree

d) Consider regulatory approaches
   Neutral

**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
   Agree

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

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

Third Priority
   d) Develop a register of persons with cognitive impairment

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence
   Agree

**Question 3:** What can be done to facilitate increased sharing of data?
   Revision of data protection legislation eg to allow greater use of clinical (healthcare provision) data for research purposes without cumbersome consent/consultee agreement requirements

**Question 4:** What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   Great in principle. Unlikely in practice given current concentration in intellectual property rights by both academic institutions and industry. Could be made a condition of public funding.

**Question 5:** Relating to point (e) do you see any risk(s) in developing centres of excellence?
   Development is inhibited elsewhere - a hub and spoke model may help. This is especially required to get access to large numbers of patients for epidemiological studies or trials

**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

Strongly 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
c) Facilitate research in areas outside university and hospital sectors

d) Encourage industry to adopt pre-competitive approach

Third Priority

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

Money talks. UK universities are very focussed on performance indicators. This inhibits early stage, more speculative, and less methodologically developed fields of study, which are seen as less productive, and this is particularly true for NDD. Research policy makers need to circumvent this by ensuring generous project, development and training funding, and an understanding of the limitations on NDD research that can make it appear less productive or less good value for money (e.g. recruitment to trials of people lacking mental capacity is very time consuming and labour intensive). NDD funding needs to be ring fenced and not in open competition with cancer, cardiovascular or mainstream genomics.

**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

Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
e) Maintain capacity for 'bottom-up' innovative funding

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

make it a requirement of public funding (cf NIH publication rules in US)

**Concluding questions**

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

patient public involvement mechanisms (but be cautious about ensuring they really do provide added value)

Complex service delivery trial regulation and guidance (GCP does not fit well)

Health Policy and health services research (these may well have greater impact on clinical practice and patient experience than you might give credit for, and offer earlier gains than more fundamental research)

You mentioned co-morbidity: delirium is a special case of this which is barely understood, and might deserve special attention

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?

Crucial area, horribly under-researched, keep up the good work
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
   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?
   Improving diagnostic accuracy to facilitate appropriate channeling for treatment trials/treatments

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
   c) Research into the needs of carers

Second Priority
   f) Understand and investigate influence of comorbidities on NDD

Third Priority
   e) Rethink approaches to care

Question 3: How would you define “care”?
   All aspects of patient management from initial presentation and diagnosis through treatment to end of life planning.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   Each patient could have a named nurse who would oversee their care from start to finish.
Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Staff in care homes should be trained to care for patients with dementia and the environment and activity schedule should be targeted to the needs of each individual.

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  
   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  
   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?

If a clinician with whom the patient is familiar raises the issue of brain donation, the patient is more likely to consider consenting.

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  
   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  
   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

**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
   - 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
   - Agree
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
     a) Improve access to, and sharing of, infrastructure and resources
   - Second Priority
     b) Improve access to patient groups, samples and data
   - Third Priority
     d) Develop a register of persons with cognitive impairment

Question 3: What can be done to facilitate increased sharing of data?
   - Encourage uploading of research methodology and data to a secure, user-friendly, web-based system.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   - Data should be open access once anonymised after the author has published the results (unless there is no plan to publish).

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   - Smaller centres could be marginalised and this could limit the degree of ingenuity in research as strong research themes within a centre of excellence dominate. Dementia patients may have to travel further to a centre of excellence. It would be better to have more centres close to patients with rigorous standards applied to ensure excellence.

**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
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
   c) Facilitate research in areas outside university and hospital sectors

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
   Neutral
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
   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
   We have used ADNI data and found this a useful means of resource sharing.

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?
   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?
   aging, cognitive impairment, early assessment, dementia

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
   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
   a) Define the term ‘care’
Third Priority
   c) Research into the needs of carers

Question 3: How would you define “care”?
   A comprehensive and disease-specific professional and nonprofessional medical and social support for patient to maintain a high quality of life and to decrease suffering

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   patient and caregiver friendly, revision of local and country policy, introducing the innovation technology, education of the population from the elementary school to understand what is a care for closest
Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

- To stimulate home care, introducing an innovative technology,
- Increase the time spending for caregivers,
- Education of caregivers, individual-oriented home adaptation,
- Accessibility to health professionals,
- Full social engagement

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
   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
   a) Increase involvement of individuals in research

Second Priority
   d) Ensure better patient selection/stratification

Third Priority
   e) Rethink approach to therapeutics

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

- Education education education of health professionals,
- Changing negative attitude of health professionals towards postmortem analysis,
- Early discussion with patients and caregivers regarding important of research,
- To have a very clear position that there is no animal model for human neurodegenerative diseases

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?

- To educate and inform population and HPs of importance,
- To increase an awareness of political structures on local or country level

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
   Strongly Agree

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

f) Focus research on rare hereditary forms of disease

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

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
   a) Understand relationship between NDD and ageing

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

NO animal model to date that can mimic neurodegeneration 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
   - Disagree

**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
   a) Improve access to, and sharing of, infrastructure and resources
Second Priority
   b) Improve access to patient groups, samples and data
Third Priority
   e) Develop centres of excellence

**Question 3:** What can be done to facilitate increased sharing of data?
   - Increase a protection of data

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

**Question 5:** Relating to point (e) do you see any risk(s) in developing centres of excellence?
   - Only if center of excellence will not serve as an educational hub for entire professional and non-professional community

**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
   - Strongly 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
   - 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
  c) Facilitate research in areas outside university and hospital sectors

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?
  increase fundings, decrease military budgets, recruiting high professional experts in regulatory agencies

**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
  c) Joint academic-industry funding models

Second Priority
  d) Simplify funding application systems

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

  to build up transregional network programs

**Concluding questions**

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

  permanent education of policy makers  
  aging is not problem of aged people only but entire society
  harmonization and synchronization of clinical and preclinical knowledge

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

  Ad 1) despite different political opinions, health should not be polarised. Trying to find the best solutions that are patient-friendly. Politician should be open for education and should listen professionals  
  Ad2) education from kindergarten level what

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

  yes but there is not enough place
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
   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
   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?

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
   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
   d) Research end of life decision making
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?

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
   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
   c) Conduct multi-centre primary prevention studies
Third Priority
   e) Rethink approach to therapeutics

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
   Strongly 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
   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
   c) Improve understanding of disease mechanisms
Second Priority
   a) Understand relationship between NDD and ageing
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?
   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
   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?  
   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  
   Agree

c) Improve data and sample collection  
   Agree

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

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

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  
   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  
   Neutral

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  
   d) Encourage industry to adopt pre-competitive approach

Second Priority  
   f) Review and update legislation on treatment

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

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
   Strongly Agree
c) Joint academic-industry funding models
   Strongly Agree
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
   b) Encourage open-access sharing of data and materials
Second Priority
   c) Joint academic-industry funding models
Third Priority
   a) Translational research needs to be promoted

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
   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?
   Getting the populations and politicians to understand the basics of clinical neuroscience is vital - it will put neuroscience up the agenda for funding

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
   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
   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”?
   The process of looking after a patient and/or carer - includes nursing, medical and services allied to medicine

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   Patients with neurological diseases under age 65 frequently do not receive adequate rehabilitation nor support at home as services are guided to over 65s
Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Depends on staffing in the community and educating and encouraging local services

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
   Neutral
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
a) Increase involvement of individuals in research
Second Priority
d) Ensure better patient selection/stratification
Third Priority
e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
   It requires a person to person conversation explaining brain donation and the potential benefits to the family and our population as a whole - most patients agree to brain donation if it is explained clearly

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?
   Education and ongoing education/social activity Exercise

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

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
   d) The biological basis of behavioural and psychological symptoms
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
 Perhaps - neurodegenerative disorders are lethal and many patients want to try something to see if it could slow or arrest the disease - there is a role for clinician-led trial

**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
    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
c) Improve data and sample collection
Second Priority
e) Develop centres of excellence
Third Priority
e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?
Ensure subsequent papers acknowledge the generous donation and include the senior author on the paper. Difficulties are surmountable

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

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
There is always the concern of ‘dumbing-down’ the other physicians and also the specialist becomes too removed from the real world of 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
    Strongly 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
    Neutral
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
  e) Rethink patent lifetime and conduct public-private clinical trials
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?
  Encourage researcher-led trials - less expensive and hypothesis-based

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  
   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
  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)
   As a busy neurologist I find it very difficult to get time to do or plan the research - there is need for more neurologist and also for research and teaching

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?
   It is frustrating to not have enough support or time to link the clinical phenotype, database, radiology and genetics with the molecular aspects etc, this comes down to not recognosing we need to prospectively collect the clinical phenotype (video etc), radiology, and pathology of our patients. Resources are needed to do this and free up some time of individuals to drive a hard bargain
**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
   Agree

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

d) Increase training for translational and clinician-scientists
   Neutral

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?

Carers

**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
   Strongly 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
   e) Rethink approaches to care

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

Third Priority
   c) Research into the needs of carers

Question 3: How would you define “care”?

Considering and responding to the physical and psychological needs of a person.

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?
Look closely at the standard of the care being provided. Educate carers. Consider a standardised qualification for carers looking after older people and those who have NDD including written papers but observed practice. Can they communicate effectively? Can they see and respond to the needs of the client? Look at the numbers of carers. Consider incentives for becoming a carer. Look at a support network for carers. Increase respite places.

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
   Neutral

d) Ensure better patient selection/stratification
   Disagree

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
   b) Promote development of non-pharmacological interventions

Third Priority
   e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
   Through education. Clinicians are not aware of trials, therefore the patients won’t be.

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
   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
   Neutral

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

Second Priority
   g) Establish pan-European population-based studies

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?
   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
   Neutral

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
   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?
   very difficult as confidentiality is the first priority. With patient’s permission upload data/details to a central server similar to the ‘nhs spine’

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

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

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
   Neutral
c) Research into the needs of carers
   Disagree
d) Research into care approaches including end of life decision-making
   Neutral
e) Rethink approaches to care
   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
   Neutral

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

Question 3: How would you define “care”?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   Focus on how to stimulate personal continuity care, ie how the same professional carerers can give service to the patient over long time.

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
   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
   Agree

Question 2: Please rank the suggestions in order of priority

First Priority
   c) Conduct multi-centre primary prevention studies

Second Priority
   b) Promote development of non-pharmacological interventions

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
   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
   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
   Neutral

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
   e) Determine the importance of genetic and environmental risk factors

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?

   b) Neuronal inflammation

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
   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
   Agree
d) Develop a register of persons with cognitive impairment
   Neutral
e) Develop centres of excellence
   Neutral

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
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
   Strongly Agree
b) Ensure greater engagement with regulators
   Strongly Disagree
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
   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
   a) Need for evidence-based policy
Second Priority
   d) Encourage industry to adopt pre-competitive approach
Third Priority
   e) Rethink patent lifetime and conduct public-private clinical trials

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
   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
   e) Maintain capacity for 'bottom-up' innovative funding
Second Priority
   d) Simplify funding application systems
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
   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?
   There is a need to acknowledge the overlap between neurodegenerative diseases and diseases which relate to them closely, like vascular cognitive impairment (and associated vascular diseases) and delirium, as well as the functional impact of neurodegenerative disease itself. There is also a need to see research and clinical practice in a lifecourse perspective, linking antenatal, postnatal, pediatric, adult and geriatric research and healthcare.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term “care”
   Disagree
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
   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
   d) Research end of life decision making
Third Priority
   e) Rethink approaches to care

Question 3: How would you define “care”?
   This is context dependent and I don’t think one definition can incorporate all meanings (adjective and noun). I would define it as 'responsibility towards someone’s needs'

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   Integrating assessments by health and social services. Ensuring regular review, including advance care planning. Systems to identify those at high risk eg of delirium, infection, rapid deterioration, to ensure plans in place about escalation of care, and indentifying those at risk eg when admitted to hospital. Ensure a current summary of functional level included for those in residential care.
Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Ensure that a choice for care at home is informed by both advantages and disadvantages. Improve care provided at home (better pay and training for paid carers, and training and support for unpaid carers (relatives)). Improved professional support eg health visitors, community psychiatric nurses etc (funding constraints have meant these are often being reduced in the UK).

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
   Disagree
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
a) Increase involvement of individuals in research
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?

Ensure a discussion is had after diagnosis (and associated support) with every patient and their carer, to offer registration for a register which would allow contact for research (with no obligation to participate). Discuss annually? Should be initiated by main supervisor of clinical care (?psychiatrist, neurologist, geriatrician, CPN) but could be followed up by research nurse to provide additional information.

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?

Role of controlling vascular risk factors or exercise on cognitive decline. Also an area for using targeted subgroups: target ‘at risk’ populations, eg due to family history, genetics, or vascular risk factors (eg diabetes, peripheral vascular disease, cardiovascular disease). Could look at impact of antenatal care on later life outcome (cohort study rather than trial, and very long time lag to results).

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
   Strongly Agree
e) Determine the importance of genetic and environmental risk factors
   Strongly Agree
f) Focus research on rare hereditary forms of disease
   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
   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
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?
   d) The biological basis of behavioural and psychological symptoms

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
   If animal models are not felt to be a useful surrogate for the clinical situation, the disease is very debilitating, and the treatment low risk.

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
      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
      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
      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
      c) Improve data and sample collection
   Third Priority
      e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?
   Need a more open culture of data sharing between researchers. This is progressing, and more collaborative research is ongoing.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   I’m in favour of open access data, but researchers who have invested time and money in collecting this should have a reasonable time period to perform the analyses predetermined, and should be acknowledged in related publications.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   If these also concentrate clinical centres then access may be difficult for people in remote areas.

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

Question 2: Please rank the suggestions in order of priority

First Priority
   a) Translational research needs to be promoted
   d) Simplify funding application systems

Second Priority
   a) Translational research needs to be promoted
   b) Encourage open-access sharing of data and materials

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
   Agree

Question 2: Please rank the suggestions in order of priority

First Priority
   d) Simplify funding application systems

Second Priority
   a) Translational research needs to be promoted
   b) Encourage open-access sharing of data and materials

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)
   Key to success will be encouraging communication between the disparate groups involved in this research (neurologists, geriatricians, psychiatrists, neuroradiologists, basic scientists, epidemiologists etc), both in the research and clinical environments.

Question 2: Do you have any comments on how to implement the above suggestion(s)?
   Encouragement to organisations to increase inter-disciplinary working. Reduced rates at conferences to non-specialists?

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
   Agree
c) Increase numbers of neurodegenerative disease (NDD) researchers
   Neutral
d) Increase training for translational and clinician-scientists
   Neutral
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”
   Neutral
b) Survey long-term care standards and provision across Europe
   Neutral
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
   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
   g) Conduct research into effects of nutrition and frailty
Second Priority
   h) Determine cost-effectiveness of healthcare pathways
Third Priority
   c) Research into the needs of carers

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
   Neutral
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  
   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 
   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?  

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?  
   Homocysteine lowering; effects of B vitamins and other antioxidants  

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  
   Neutral 

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  
   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 
   Neutral  

Question 2: Please rank the suggestions in order of priority 

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

Second Priority 
   c) Improve understanding of disease mechanisms 

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? 

b) Neuronal inflammation  

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  
   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?
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
   Neutral
b) Improve access to patient groups, samples and data
   Neutral
c) Improve data and sample collection
   Neutral
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
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  
   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?

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  
   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  
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority  
   c) Research into the needs of carers
Second Priority  
   f) Understand and investigate influence of comorbidities on NDD
Third Priority  
   h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define “care”?
   Care, in my mind, encompasses everything that an individual with dementia needs beyond what the family provides while with family and everything when taken care by other caregivers i.e. in institution.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   Strongly believe that it should be centered around general practitioners as this improved the quality of life of patients, their families and reduced the cost without significantly the quality of care if done appropriately.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
   Dementia patients should get all and more help when at home as once they leave their homes everything is different for them plus care becomes more expansive.

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  
   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
   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?
   Better education, marketing.

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?
   Though call. We need more basic research to get good clues about what to probe for.

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  
   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  
   Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority
   c) Improve understanding of disease mechanisms

Second Priority
   a) Understand relationship between NDD and ageing

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.
   No way. I have been in the Alzheimer’s and related disease field for over 15 years as a basic neuroscientist with several years of bench work and also as a cognitive neurologist seeing patients. Cell models are great, they contributed a lot in the early 90s to learn about APP, abeta, etc....and still play an important role, but jumping from cells (i.e. non physiological amounts of abetadumped onto kidney cells?) strength to humans I don't think this is scientifically sound. Moreover, even the best animal models are far away from real disease. Cell or animal models are good for testing very specific disease related questions and animal models are an important step in designing human research.
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  
   Strongly 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  
   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  
   a) Improve access to, and sharing of, infrastructure and resources
Second Priority  
   b) Improve access to patient groups, samples and data
Third Priority  
   c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?  
   Change the mindset in Europe. In my example, when I returned back home with reasonable knowledge and publications in journals including Science and Neuron no one cared, even more, some tried to block my every attempt to continue research. And I know this happens in many places across Europe.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?  
   This needs good regulation and control.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?  
   No, we absolutely need them, but in Europe this will lead to fights as everyone will want to develop a Centre of excellence.

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  
   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  
   Strongly 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
  a) Need for evidence-based policy
Second Priority
  c) Facilitate research in areas outside university and hospital sectors
Third Priority
  e) Rethink patent lifetime and conduct public-private clinical trials

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

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
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
  d) Simplify funding application systems
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
  Maybe it could be achieved in the same way as companies breeding animal models and stem cells work in US?

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)
  Think nepotism and despotism are more typical of Europe than of the US and this is in our disadvantage, we should find ways to get rid of it.

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
   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?
   I think that use of neuropsychological tests in current clinical practice should be based on highest quality of normative population data.

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
   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
   g) Conduct research into effects of nutrition and frailty
Second Priority
   b) Survey long-term care standards and provision across Europe
Third Priority
   h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define “care”?
   The care term means the overall treatments (pharmacological and non-pharmacological) with which the patient and caregiver have been treated.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
   From the disease management point of view I think that social and health services should be considered together.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
   We must choose the treatments based on good evidences.

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
   Agree
d) Ensure better patient selection/stratification
   Strongly Agree
e) Rethink approach to therapeutics
   Strongly Agree
f) Support for high-risk projects
   Strongly Disagree

Question 2: Please rank the suggestions in order of priority
First Priority
   f) Support for high-risk projects
Second Priority
   d) Ensure better patient selection/stratification
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?
   I think that an serious national project on biobank should be implemented in each european country.

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?
   For example the conversion from mild cognitive impairment to dementia. Or the conversion from normal cognitive health status to MCI.

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
   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
   Strongly Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   a) Understand relationship between NDD and ageing
Second Priority
   e) Determine the importance of genetic and environmental risk factors
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?
   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
   I think that only in very particular conditions the animal models may be ignored: the results from cell-based models should be particularly positive and consistent.

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 Disagree
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?
   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
   a) Improve access to, and sharing of, infrastructure and resources
Second Priority
   e) Develop centres of excellence
Third Priority
   c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?
   I think that an multidisciplinary consortium should be created.

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?
   I think that an specific protocol should be performed.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
   Yes, I think the the centres of excellence should be prevalently public.

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
   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
   Strongly Agree
e) Rethink patent lifetime and conduct public-private clinical trials
   Strongly Agree
f) Review and update legislation on treatment
   Disagree
g) Review and update legislation on privacy and data disclosure
   Strongly 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
   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?

I think that regulatory approaches should encourage and consider the use of valid surrogate end-point in all clinical trials.

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

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

**Concluding questions**

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

I suggest a higher quality of basic research because only when there are solid evidences in this sector, they should be transferred in the clinical research.

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

I think that a public health perspective should be conserved in this specific area of research because the risk of a disease mongering situation may be always present.

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

I think that a major coordination of all european and national projects on neurodegenerative diseases is urgently necessary.