Funding agency, policy-maker & regulator respondees

Responses from organisations

ID code	Organisation	Country	Page
1627	European Alliance for Restless Legs Syndrome	Netherlands	2
1727	Royal Dutch Society for Physical Therapy (KNGF)	Netherlands	6
2092	Vereniging Gehandicaptenzorg Nederland	Netherlands	10
2093	Swedish Dementia Center	Sweden	14

Anonymous responses from organisations

ID code	Country	Page
1944	France	18

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

UID
  1627
Title
  Ms
First Name
  Joke
Surname
  Jaarsma
Category of respondee
  Funding agency, policy-maker or regulator
Institution/Organisation/Company
  European Alliance for Restless Legs Syndrome
Replying on behalf of organisation/company?
  On behalf of my organisation
Country
  Netherlands

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
  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?
  Restless Legs Syndrome. Still too little awareness of this sometimes devastating disease which has high prevalence and due to significant underdiagnosis causes unnecessary suffering at (so far unknown) very high cost to society.

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

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

Question 3: How would you define "care"?
  Care: The efforts / attempts to keep/bring things in good condition, or as good as possible.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
  A more intensive dialogue between doctors and patients will lead to improvement of health care and better insight into and understanding of NDD

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
　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
　e) Rethink approach to therapeutics
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?
　Through active collaboaration between science and patient groups

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

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
　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
　Neutral
h) Develop more representative animal and cell-based models of disease
　Agree

Question 2: Please rank the suggestions in order of priority
First Priority
　a) Understand relationship between NDD and ageing
Second Priority
　b) Improve understanding of disease stages
Third Priority
　c) Improve understanding of disease mechanisms

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

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
> Neutral

d) Develop a register of persons with cognitive impairment
> Neutral

e) Develop centres of excellence
> Agree

Question 2: Please rank the suggestions in order of priority
First Priority
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 forsee difficulties, how can we overcome these?
> This should happen indeed. The problem are the commercial publishers who hold copyright on the materials in their books, journals and databases. On the other hand they also add value to the publication process. Thus, this problem cannot easily be overcome. Large-scale contracts - including patient organisations - might be an option.

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

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
> Disagree

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

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?
> Make negative results from clinical trials public?

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

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
    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
    I have been a publisher with Elsevier Science. Now retired. I have witnessed the revolution in the publishing process after Internet started. The scientific publishing business needed to adjust to the new world, at the same time had to safeguard its own existence. The additional value it has built over more than a century cannot be neglected. Industry and academia already have contracts for online access. The business model used for e.g. scientific societies (members) can be explored.

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)
    The European Alliance for Restless Legs Syndrome have undertaken a study among the members of patient groups in nine European countries. More countries are underway. The outcome is of interest to industry (market access), to health economy (data a.o. on sick leave and disability), and to the medical profession at large. Making use of the patient populations as far as I know is not done in any structured way. Thus, giving patients a voice and at the same time making use of their organisations might be worth looking into.

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?

UID
1727
Title
Dr.
First Name
Victorine
Surname
de Graaf-Peters
Category of respondee
Funding agency, policy-maker or regulator
Institution/Organisation/Company
Royal Dutch Society for Physical Therapy (KNGF)
Replying on behalf of organisation/company?
On behalf of my organisation
Country
Netherlands

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

Question 2: Please rank the suggestions in order of priority
First Priority
f) Understand and investigate influence of comorbidities on NDD
Second Priority
g) Conduct research into effects of nutrition and frailty
Third Priority
b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?
Free translation WHO Care is an approach that improves the quality of life of patients and their families facing the problem associated with illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

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
> Strongly Agree
c) Conduct multi-centre primary prevention studies
> Strongly Agree
d) Ensure better patient selection/stratification
> Neutral
e) Rethink approach to therapeutics
> Agree
f) Support for high-risk projects
> Neutral

Question 2: Please rank the suggestions in order of priority
First Priority
> b) Promote development of non-pharmacological interventions
Second Priority
> c) Conduct multi-centre primary prevention studies
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
> Neutral
c) Improve understanding of disease mechanisms
> Agree
d) Develop an improved understanding of the genetic basis for NDD
> Disagree
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
> c) Improve understanding of disease mechanisms
Second Priority
> a) Understand relationship between NDD and ageing
Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
> 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
Strongly Agree
b) Redefine and harmonise clinical endpoints and outcomes
Agree
c) Develop new biomarkers
Disagree
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
Agree
d) Develop a register of persons with cognitive impairment
Disagree
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
e) Develop centres of excellence
Third Priority

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

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

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

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
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
Neutral
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
b) Ensure greater engagement with regulators
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?

UID
2092
Title
Professor
First Name
Heleen
Surname
Dupuis
Category of respondee
Funding agency, policy-maker or regulator
Institution/Organisation/Company
Vereniging Gehandicaptenzorg Nederland
Replying on behalf of organisation/company?
On behalf of my organisation
Country
Netherlands

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
d) Increase training for translational and clinician-scientists
Agree
e) Increase numbers of post-doctoral level researchers
Agree

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

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

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term "care"
Disagree
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
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
f) Understand and investigate influence of comorbidities on NDD

Question 3: How would you define "care"?

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

Question 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
  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
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
  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
  Agree

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

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
  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
  Strongly Agree
b) Redefine and harmonise clinical endpoints and outcomes
  Strongly Agree

c) Develop new biomarkers
   Agree
d) Consider regulatory approaches
   Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?
   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
   Neutral
b) Improve access to patient groups, samples and data
c) Improve data and sample collection
   Neutral
d) Develop a register of persons with cognitive impairment
   Neutral
e) Develop centres of excellence
   Agree

Question 2: Please rank the suggestions in order of priority
First Priority
   e) Develop centres of excellence
Second Priority
Third Priority

Question 3: What can be done to facilitate increased sharing of data?
   When the culture in knowledge management is no longer anglo-saxian (knowledge as a monopoly) and becomes 'rhineland' (sharing of knowlegdge).

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

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

Policy, regulation and legislation

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

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

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

Concluding questions

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

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?
1) We would like to draw attention to the comorbidity of Downs syndrome and Alzheimer disease. Because of the increase of ageing people with Down's syndrome this is a main challenge in the field of intellectual disabilities. More research on this subject is needed.   2) Besides that in the field of intellectual disabilities as to participating in research the capacity of consent of is a big issue.

UID
2093
Title
Dr
First Name
Wilhelmina
Surname
Hoffman
Category of respondee
Funding agency, policy-maker or regulator
Institution/Organisation/Company
Swedish Dementia Center
Replying on behalf of organisation/company?
On behalf of my organisation
Country
Sweden

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
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
c) Research into the needs of carers
Second Priority
e) Rethink approaches to care
Third Priority
d) Research end of life decision making

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
　　Strongly Agree
c) Conduct multi-centre primary prevention studies
　　Strongly Agree
d) Ensure better patient selection/stratification
　　Neutral
e) Rethink approach to therapeutics
　　Strongly Agree
f) Support for high-risk projects
　　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?

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
　　Agree

Question 2: Please rank the suggestions in order of priority
First Priority
　　a) Understand relationship between NDD and ageing
Second Priority
　　b) Improve understanding of disease stages
Third Priority
　　c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
　　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
   Strongly 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
   Disagree
e) Develop centres of excellence
   Strongly Agree

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

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

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

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

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points
a) Need for evidence-based policy
   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
   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
   a) Need for evidence-based policy
Second Priority
   d) Encourage industry to adopt pre-competitive approach
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
    Strongly Agree
c) Joint academic-industry funding models
    Neutral
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
    e) Maintain capacity for 'bottom-up' innovative funding
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?

UID
1944
Category of respondee
    Funding agency
Country
    France
Replying on behalf of organisation/company?
    Yes

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

c) Increase numbers of neurodegenerative disease (NDD) researchers

d) Increase training for translational and clinician-scientists

e) Increase numbers of post-doctoral level researchers

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

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"

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

c) Research into the needs of carers

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

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

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

Second Priority

Third Priority

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

b) Promote development of non-pharmacological interventions

c) Conduct multi-centre primary prevention studies

d) Ensure better patient selection/stratification

e) Rethink approach to therapeutics

f) Support for high-risk projects

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

b) Improve understanding of disease stages

c) Improve understanding of disease mechanisms

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

e) Determine the importance of genetic and environmental risk factors

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

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

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

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 forsee difficulties, how can we overcome these?

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

Policy, regulation and legislation

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

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

Second Priority

Third Priority

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

Funding and funding mechanisms

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

Question 2: Please rank the suggestions in order of priority
First Priority
    c) Joint academic-industry funding models
Second Priority
    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?