Directory of charity and patient group respondees

Responses from organisations

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1411	French Federation for Brain Research (FRC) *	France	2
1437	Alzheimer's Research UK	United Kingdom	6
1616	The Alzheimer Society of Ireland	Ireland	10
1626	European Parkinson's Disease Association (EPDA)	European-wide	14
1956	Association France Alzheimer	France	18
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2025	The Cure Parkinson's Trust	United Kingdom	26
2152	French Federation for Brain Research (FRC) *	France	30
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	* The French Federation for Brain Research made two submissions to the online consultation		

Anonymous responses from organisations

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Responses from individuals

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Anonymous responses from individuals

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1878	United Kingdom	50
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One additional response was received from an organisation which requested that their submission be used for no other purpose than in the overall analysis of responses.

UID
1411
Title
Mr
First Name
Arnaud
Surname
BRUNEL
Category of respondee
Charity organisation or patient group
Institution/Organisation/Company
FRC French Federation for Brain Research
Replying on behalf of organisation/company?
On behalf of my organisation
Position at organisation
President
Country
France

Education, training and collaboration

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

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

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

Health and social care issues

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

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

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

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

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

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

Disease cause, mechanisms and models

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

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

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

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

Diagnosis, disease definitions and outcome measures

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

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
Agree
b) Improve access to patient groups, samples and data
Agree
c) Improve data and sample collection
Strongly Agree
d) Develop a register of persons with cognitive impairment
Agree
e) Develop centres of excellence
Strongly Agree

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

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

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

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

Policy, regulation and legislation

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

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

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

Funding and funding mechanisms

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

d) Simplify funding application systems
Strongly Agree
e) Maintain capacity for 'bottom-up' innovative funding
Strongly Agree

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

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

Concluding questions

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

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

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

UID
1437
Title
Dr
First Name
Simon
Surname
Ridley
Category of respondee
Charity organisation or patient group
Institution/Organisation/Company
Alzheimer's Research UK
Replying on behalf of organisation/company?
On behalf of my organisation
Position at organisation
Head of Research
Country
United Kingdom

Education, training and collaboration

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

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

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

Health and social care issues

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

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

Question 3: How would you define "care"?
　I don't have a firm definition

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

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

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

Prevention/treatment strategies and trials

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

Agree
b) Promote development of non-pharmacological interventions

Agree
c) Conduct multi-centre primary prevention studies

Agree
d) Ensure better patient selection/stratification

Agree
e) Rethink approach to therapeutics

Agree
f) Support for high-risk projects

Neutral

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

a) Increase involvement of individuals in research
Second Priority

d) Ensure better patient selection/stratification
Third Priority

c) Conduct multi-centre primary prevention studies

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

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

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

I think the most important aspect is time. Hard as it is for funding agencies, any studies looking at modifiable risk factors in mid-life need to have long-term follow up to be of any value.

Disease cause, mechanisms and models

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

Agree
b) Improve understanding of disease stages

Agree
c) Improve understanding of disease mechanisms

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

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

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

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

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

Strongly Agree

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

c) Improve understanding of disease mechanisms
Second Priority

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

g) Establish pan-European population-based studies

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

c) Mechanisms of neuronal death and dysfunction

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

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

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

Policy, regulation and legislation

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

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

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

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

Funding and funding mechanisms

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

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

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

Concluding questions

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

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

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

UID
  1616
Title
  Ms
First Name
  Grainne
Surname
  McGettrick
Category of respondee
  Charity organisation or patient group
Institution/Organisation/Company
  The Alzheimer Society of Ireland
Replying on behalf of organisation/company?
  On behalf of my organisation
Position at organisation
  Research and Policy Officer
Country
  Ireland

Education, training and collaboration

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

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

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

Health and social care issues

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

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

Question 3: How would you define "care"?
  I tihnk we need to define care according to those who provide it - i.e paid professional carers or family carers (informal carers)

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

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Care at home should be part of a suite of services available to the person with NDD; there should be an integrated care pathway developed combining all of the clinical and care elements in an integrated fashion with joined up planning and a co-ordinated approach.

Prevention/treatment strategies and trials

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

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

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?
We need to be able to 'sell' the benefits to the patient and their family in a much more accessible way. The Health Care Professional involved in the care of that person is a critical influencer and they need to be bought into the research agenda.

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

Disease cause, mechanisms and models

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

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

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

Question 4: What are your views on making data open access? If you 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
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?

UID
1626
Title
Ms
First Name
Lizzie
Surname
Graham
Category of respondee
Charity organisation or patient group
Institution/Organisation/Company
European Parkinson's Disease Association
Replying on behalf of organisation/company?
On behalf of my organisation
Position at organisation
Secretary General
Country
Europe-wide organisation

Education, training and collaboration

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

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

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?
Improve dialogue between researchers and the wider population to achieve better general awareness and knowledge of research and increase understanding of how participation can improve research quality and progress.   To reduce the many hurdles that exist within the long and complex process of progressing a new treatment from the laboratory bench to the bedside.

Health and social care issues

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

Question 2: Please rank the suggestions in order of priority
First Priority
e) Rethink approaches to care
Second Priority
h) Determine cost-effectiveness of healthcare pathways
Third Priority
a) Define the term 'care'

Question 3: How would you define "care"?

Many people with Parkinson's believe 'gold standard care' should involve a multidisciplinary team with care tailored to their specific needs and those of their family and carers. Such multidisciplinary treatment may involve a number of allied health specialists , including physiotherapists, occupational therapists and speech and language therapists as well as support and advice from dieticians, social workers and sexologists to complement standard medical treatment in the management of both motor and non-motor symptoms. While the neurologist determines disease severity and optimises medical treatment to reduce symptoms, allied health therapists work to minimise the impact of the disease process and improve the person's participation in everyday activities.

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

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

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

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

Prevention/treatment strategies and trials

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

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

There is a a great deal of mis-conception serious lack of understanding as to the importance and necessity for research and donation of brain material.   Therefore there should be an innovative and improved focus on awareness and education to the general public to dispel the myths.

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

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
Agree
b) Improve understanding of disease stages
Strongly Agree
c) Improve understanding of disease mechanisms
Strongly Agree
d) Develop an improved understanding of the genetic basis for NDD
Strongly Agree
e) Determine the importance of genetic and environmental risk factors
Strongly Agree

f) Focus research on rare hereditary forms of disease
  Neutral
g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups
  Strongly Agree
h) Develop more representative animal and cell-based models of disease
  Agree

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

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

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

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

Policy, regulation and legislation

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

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

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

Funding and funding mechanisms

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

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

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

Concluding questions

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

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

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

UID
  1956
Title
  Ms
First Name
  Marie Odile
Surname
  Desana
Category of respondee
  Charity organisation or patient group
Institution/Organisation/Company
  Association France Alzheimer
Replying on behalf of organisation/company?
  On behalf of my organisation
Position at organisation
  President
Country
  France

Education, training and collaboration

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

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

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

Health and social care issues

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

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

Question 3: How would you define "care"?

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

including the population at the beginning of the disease

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

Prevention/treatment strategies and trials

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

Question 2: Please rank the suggestions in order of priority
First Priority
b) Promote development of non-pharmacological interventions
Second Priority
c) Conduct multi-centre primary prevention studies
Third Priority
a) Increase involvement of individuals in research

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

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

Disease cause, mechanisms and models

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

Question 2: Please rank the suggestions in order of priority
First Priority
a) Understand relationship between NDD and ageing
Second Priority
c) Improve understanding of disease mechanisms
Third Priority
g) Establish pan-European population-based studies

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

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

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

Policy, regulation and legislation

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

Question 2: Please rank the suggestions in order of priority
First Priority
> a) Need for evidence-based policy

Second Priority
    c) Facilitate research in areas outside university and hospital sectors
Third Priority
    g) Review and update legislation on privacy and data disclosure

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

Funding and funding mechanisms

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

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

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

Concluding questions

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

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

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

UID
1990
Title
Mrs
First Name
Anne Stubbe
Surname
Arndal
Category of respondee
Charity organisation or patient group
Institution/Organisation/Company
Alzheimerforeningen
Replying on behalf of organisation/company?
On behalf of my organisation
Position at organisation
Chairman
Country
Denmark

Education, training and collaboration

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

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

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

Health and social care issues

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

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

Question 3: How would you define "care"?
To ensure the wellbeing of the person with dementia.   It should be seen in a bio-psycho-societalcontext.
Possibilities for the demented person to live as full a life as possible at each actual stage of the disease is

important. So care differs through the course of the disease.   Support in the start, later more care in the usual content of the word is needed.

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

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

Prevention/treatment strategies and trials

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

Question 2: Please rank the suggestions in order of priority
First Priority
e) Rethink approach to therapeutics
Second Priority
b) Promote development of non-pharmacological interventions
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?
More information about the possibilities to enregister into trials with new medicin.   And more information about the how importent it is to have materail from brains, both normal and diseased, to help solve the riddle of the causes for dementia. So overall: information to the public and more specific to groups of patients and their relatives.

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

Disease cause, mechanisms and models

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

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

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

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

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

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

Policy, regulation and legislation

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

g) Review and update legislation on privacy and data disclosure
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
Strongly Agree
b) Encourage open-access sharing of data and materials
Strongly Agree
c) Joint academic-industry funding models
Strongly Agree
d) Simplify funding application systems
Strongly Agree
e) Maintain capacity for 'bottom-up' innovative funding
Agree

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

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

Concluding questions

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

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

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

UID
2025
Title
Miss
First Name
Helen
Surname
Matthews
Category of respondee
Charity organisation or patient group
Institution/Organisation/Company
The Cure Parkinson's Trust
Replying on behalf of organisation/company?
On behalf of my organisation
Position at organisation
Coordinator
Country
United Kingdom

Education, training and collaboration

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

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

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

Health and social care issues

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

Question 2: Please rank the suggestions in order of priority
First Priority
f) Understand and investigate influence of comorbidities on NDD
Second Priority
g) Conduct research into effects of nutrition and frailty
Third Priority
h) Determine cost-effectiveness of healthcare pathways

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

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

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

Prevention/treatment strategies and trials

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

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

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

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

Disease cause, mechanisms and models

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

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

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?
   a) Interactions between cells and their surrounding intra- and extracellular environment

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

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

Diagnosis, disease definitions and outcome measures

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

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Agree

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

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

Data, registries, repositories and centres

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

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

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

b) Improve access to patient groups, samples and data

Second Priority

e) Develop centres of excellence

Third Priority

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

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

Link national patient records across Europe - an IT issue

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

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

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

None

Policy, regulation and legislation

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

Agree

b) Ensure greater engagement with regulators

Strongly Agree

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

Strongly Agree

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

Agree

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

Strongly Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

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

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

Funding and funding mechanisms

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

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

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

Concluding questions

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

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

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

UID
2152
Title
Mrs
First Name
Elisabeth
Surname
ILINSKI
Category of respondee
Charity organisation or patient group
Institution/Organisation/Company
FRENCH FEDERATION FOR BRAIN RESEARCH (FRC)
Replying on behalf of organisation/company?
On behalf of my organisation
Position at organisation
President
Position at organisation
General Manager
Country
France

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
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?
A government national information campaign promoting the necessity for more funds to be invested in neurosciences.

Health and social care issues

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

Question 2: Please rank the suggestions in order of priority
First Priority
h) Determine cost-effectiveness of healthcare pathways
Second Priority
b) Survey long-term care standards and provision across Europe
Third Priority
d) Research end of life decision making

Question 3: How would you define "care"?

Trying to help patients not to suffer, keeping their dignity, end their life being listened, understood and respected.

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

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

Enable families who accept to take care of patients at their home to find a dedicated place to "make a break", tell their fears and difficulties, and be supported by professionals trained for that.

Prevention/treatment strategies and trials

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

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

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

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

Disease cause, mechanisms and models

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

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

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

   a) Interactions between cells and their surrounding intra- and extracellular environment

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

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

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

Policy, regulation and legislation

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

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

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

Funding and funding mechanisms

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

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

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

Concluding questions

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

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

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

UID
2155
Title
Mrs
First Name
Amanda
Surname
Worpole
Category of respondee
Charity organisation or patient group
Institution/Organisation/Company
European Federation of Neurological Associations (EFNA)
Replying on behalf of organisation/company?
On behalf of my organisation
Position at organisation
Executive Director
Country
European-wide organisation

Education, training and collaboration

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

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

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

Health and social care issues

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

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

Question 3: How would you define "care"?
Provision of whatever is needed to support an individual's best possible quality of life - physical, mental, psychological, emotional.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
Provision of interim care for the relief of informal carers; best practice guidelines for care in hospitals both short and long term.

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

Prevention/treatment strategies and trials

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

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

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

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

Disease cause, mechanisms and models

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

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

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

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable
> Not sure

Diagnosis, disease definitions and outcome measures

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

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

c) Develop new biomarkers
> Strongly Agree

d) Consider regulatory approaches
> Strongly Agree

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

Data, registries, repositories and centres

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

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

c) Improve data and sample collection
> Agree

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

e) Develop centres of excellence
> Strongly Agree

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

Second Priority
> d) Develop a register of persons with cognitive impairment

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

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

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

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

Policy, regulation and legislation

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

b) Ensure greater engagement with regulators
> Agree

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

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

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

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

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

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

Funding and funding mechanisms

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

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

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

Concluding questions

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

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

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

Category of respondee
Charity organisation or patient group
Country
Netherlands
Replying on behalf of organisation/company?
On behalf of my organisation

Education, training and collaboration

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

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

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

Health and social care issues

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

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

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

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

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

Prevention/treatment strategies and trials

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

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

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

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

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

Disease cause, mechanisms and models

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

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

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

Question 4: What are your views on making data open access? If you 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
Agree
e) Rethink patent lifetime and conduct public-private clinical trials
Agree
f) Review and update legislation on treatment
Agree
g) Review and update legislation on privacy and data disclosure
Agree

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

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

Funding and funding mechanisms

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

Strongly Agree

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

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

Concluding questions

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

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

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

UID
2154
Category of respondee
  Charity organisation or patient group
Country
  Netherlands
Replying on behalf of organisation/company?
  On behalf of my organisation

Education, training and collaboration

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

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

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

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term "care"
b) Survey long-term care standards and provision across Europe
c) Research into the needs of carers
  Strongly Agree
d) Research into care approaches including end of life decision-making
e) Rethink approaches to care
  Agree
f) Understand and investigate influence of comorbidities
  Agree
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
  f) Understand and investigate influence of comorbidities on NDD
Second Priority
  c) Research into the needs of carers
Third Priority
  e) Rethink approaches to care

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

Strongly 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
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?
Take patient needs into account 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?

Disease cause, mechanisms and models

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

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

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

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

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

Policy, regulation and legislation

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

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

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

Funding and funding mechanisms

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

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

    a) Translational research needs to be promoted
Second Priority
    e) Maintain capacity for 'bottom-up' innovative funding
Third Priority
    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?

UID
  1855
Title
  Mrs
First Name
  Jenni
Surname
  McCabe
Category of respondee
  Charity organisation or patient group
Institution/Organisation/Company
  Parkinson's UK
Replying on behalf of organisation/company?
  As a private individual
Country
  United Kingdom

Education, training and collaboration

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

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

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

Health and social care issues

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

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

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

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

> I would suggest a menu of services available is provided including all facets of care such as healthcare, social services, volunteer groups, support groups, helplines etc

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

Prevention/treatment strategies and trials

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

b) Promote development of non-pharmacological interventions
> Neutral

c) Conduct multi-centre primary prevention studies
> Agree

d) Ensure better patient selection/stratification
> Neutral

e) Rethink approach to therapeutics
> Agree

f) Support for high-risk projects
> Neutral

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

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

Third Priority
> a) Increase involvement of individuals in research

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

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

Disease cause, mechanisms and models

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

b) Improve understanding of disease stages
> Neutral

c) Improve understanding of disease mechanisms
> Neutral

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

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

f) Focus research on rare hereditary forms of disease
> Neutral

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

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

Question 2: Please rank the suggestions in order of priority
First Priority
> d) Develop an improved understanding of the genetic basis

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

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

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

Question 4: What are your views on making data open access? If you 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
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?

UID
1878
Category of respondee
    Charity organisation or patient group
Replying on behalf of organisation/company?
    As a private individual
Country
    United Kingdom

Education, training and collaboration

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

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

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

Health and social care issues

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

Question 2: Please rank the suggestions in order of priority
First Priority
    c) Research into the needs of carers
Second Priority
    d) Research end of life decision making
Third Priority
    b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

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

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

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

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

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points
a) Understand relationship between neurodegenerative disease and ageing
Agree
b) Improve understanding of disease stages
Strongly Agree
c) Improve understanding of disease mechanisms
Agree
d) Develop an improved understanding of the genetic basis for NDD
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
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
b) Improve understanding of disease stages
Second Priority
c) Improve understanding of disease mechanisms
Third Priority
e) Determine the importance of genetic and environmental risk factors

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

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

Diagnosis, disease definitions and outcome measures

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

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

Data, registries, repositories and centres

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

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

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

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

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

Policy, regulation and legislation

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

Question 2: Please rank the suggestions in order of priority
First Priority
c) Facilitate research in areas outside university and hospital sectors
Second Priority
d) Encourage industry to adopt pre-competitive approach
Third Priority
a) Need for evidence-based policy

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

Funding and funding mechanisms

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

d) Simplify funding application systems
   Agree
e) Maintain capacity for 'bottom-up' innovative funding
   Agree

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

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

Concluding questions

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

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

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

Category of respondee
Charity organisation or patient group
Country
Netherlands
Replying on behalf of organisation/company?
As a private individual

Education, training and collaboration

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

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

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

Health and social care issues

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

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

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points
a) Increase involvement of individuals in research
Strongly Agree
b) Promote development of non-pharmacological interventions
Agree
c) Conduct multi-centre primary prevention studies
Strongly Agree

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

Question 2: Please rank the suggestions in order of priority
First Priority
a) Increase involvement of individuals in research
Second Priority
e) Rethink approach to therapeutics
Third Priority
f) Support for high-risk projects

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

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

Disease cause, mechanisms and models

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

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

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

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

Diagnosis, disease definitions and outcome measures

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

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

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

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

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

Policy, regulation and legislation

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

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

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

Funding and funding mechanisms

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

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

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

Concluding questions

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

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

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