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An additional 9 responses were received from individuals who requested that their submission be used for no other purpose than in the overall analysis of responses.

UID

1619

Title

Dr

First Name

Jean

Surname

Waters

Category of respondee

Person with Motor Neuron Disease

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?

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?

embedding research within clinical care. Encourage more clinician -scientists alongside changing public expectations with regard to the anonymised use of their health data and properly disseminating results from using it.

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

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

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

Second Priority

e) Rethink approaches to care

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

the sustaining of an individual with the goal of giving best possible quality of life.

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

improving co-ordination of an individual's care to ensure timely and appropriate provision of services for their needs.

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

compare and contrast home care v institutional care , both in quality and cost effectiveness

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

Neutral

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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?

Allow clinic time to explain and give them literature and the chance to reconsult.

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

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

a) Understand relationship between NDD and ageing

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

c) Mechanisms of neuronal death and dysfunction

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Agree
- c) **Develop new biomarkers**
Strongly Agree
- d) **Consider regulatory approaches**
Strongly Agree

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

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

Data, registries, repositories and centres

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Improve data and sample collection

Second Priority

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

Third Priority

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

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

- open access publishing and publishing negative results , not just positive.

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

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

Policy, regulation and legislation

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

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

- b) Ensure greater engagement with regulators

Second Priority

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

Third Priority

- a) Need for evidence-based policy

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

streamline regulations to ease studies through especially in multi-centre trials

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

a) Translational research needs to be promoted

Third Priority

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)

research is hampered by huge bureaucratic hurdles. A streamlining of the processes so that the wheel isn't constantly being reinvented!

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

combined acceptance that if a study has passed all ethics , peer group review and funding demands , individual R&D departments act as monitors and facilitators and not as more obstacles to overcome.

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

UID

1713

Title

Dr

First Name

Peter

Surname

Reijngoud

Category of respondee

Person with Restless Leg's Syndrome

Country

Netherlands

Education, training and collaboration

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

a) Improve dialogue between researchers and the wider population

Strongly Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Agree

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

a) Improve dialogue between researchers and wider population

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

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

a) Define the term "care"

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?

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

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Rethink approach to therapeutics

Second Priority

- d) Ensure better patient selection/stratification

Third Priority

- a) Increase involvement of individuals in research

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

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**
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**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Understand relationship between NDD and ageing

Second Priority

- b) Improve understanding of disease stages

Third Priority

- c) Improve understanding of disease mechanisms

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

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

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**
Strongly Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Agree
- c) **Develop new biomarkers**

Agree

d) Consider regulatory approaches

Agree

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

b) Linking to treatment responses

Data, registries, repositories and centres

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

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

Neutral

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

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

c) Improve data and sample collection

Third Priority

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

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

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

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

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

d) Simplify funding application systems

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Concluding questions

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

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

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

UID

1734

Title

Ms

First Name

Christy

Surname

Brom

Category of respondee

Carer for person with sporadic Creutzfeldt-Jakob disease

Country

United States

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

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?

the medical profession needs to be able to know how distinguish between Parkinson's/Alzheimers/CJD when making a diagnosis on a patient. They need to know what abnormalities to look for on MRI's, CJD is very often misdiagnosed.

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

Neutral

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

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Strongly 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

d) Research end of life decision making

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

looking at a patient's quality-of-life and assessing how you, the care-giver, can improve it.....if need be

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

my family and I received top-notch care/and support from the hospital where our mother was during her illness with CJD, mother died in the hospital, so we didn't need hospice/home-care assistance. The hospital staff was compassionate and supportive, and the infectious disease specialist on Mom's case was very

knowledgeable about CJD. So, care systems should have compassionate, supportive and knowledgeable doctors/nurses on their staff.

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

Again, mother died in the hospital, we didn't require home-care assistance, so I can't answer this.

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Neutral

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

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

My family and I had an autopsy performed on our mother after her death from CJD, this was to prove 100% that she did have sCJD, we also donated tissue samples to the Nat'l Prion Disease Pathology Surveillance Center in Cleveland, Ohio (who also confirmed mother's sCJD). While we had to problems w/an autopsy, or donating samples, there are families out there who have issues about having an autopsy done/donating samples. This could be religious beliefs, etc. So this is a tricky area for families w/CJD patients.

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

Neutral

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

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Understand relationship between NDD and ageing

Second Priority

b) Improve understanding of disease stages

Third Priority

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?

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

Diagnosis, disease definitions and outcome measures

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

- a) Redefine and standardise disease definitions and diagnosis**
Strongly Agree
- b) Redefine and harmonise clinical endpoints and outcomes**
Agree
- c) Develop new biomarkers**
Neutral
- 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**
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**
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

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

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Need for evidence-based policy

Second Priority

f) Review and update legislation on treatment

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

Neutral

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Neutral

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

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

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

Concluding questions

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

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

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

I thank you for allowing CJD Aware! an opportunity to look at this survey and answer some of the questions.

UID
1819
Title
Mrs
First Name
Valerie
Surname
Wilden
Category of respondee
Person with Parkinson's
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?

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

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Conduct research into effects of nutrition and frailty

Second Priority

- c) Research into the needs of carers

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**
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

- a) Increase involvement of individuals in research

Second Priority

- d) Ensure better patient selection/stratification

Third Priority

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

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

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

- a) Redefine and standardise disease definitions and diagnosis
- b) Redefine and harmonise clinical endpoints and outcomes
- c) Develop new biomarkers
- d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted**
- b) Encourage open-access sharing of data and materials**
- c) Joint academic-industry funding models**
- d) Simplify funding application systems**
- e) Maintain capacity for 'bottom-up' innovative funding**

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

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

Concluding questions

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

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

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

UID
1821
Title
Mr
First Name
Alun
Surname
Morgan
Category of respondee
Person with Parkinson's
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**
Agree
- e) **Increase numbers of post-doctoral level researchers**
Agree

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

- a) **Improve dialogue between researchers and wider population**

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

Health and social care issues

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

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

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

Question 3: How would you define "care"?

Assisting people with Parkinson's to lead a normal a life as possible. The carer should listen, help when help is requested or needed. The carer shouldn't assume that the needs of the person they care for are the same as theirs.

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?

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- c) Conduct multi-centre primary prevention studies

Third Priority

- f) Support for high-risk projects

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

- Have Researchers and Patients speak to school pupils and undergraduates

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

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Establish pan-European population-based studies

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- d) Develop an improved understanding of the genetic basis

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

- b) Neuronal inflammation

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Agree

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

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

Data, registries, repositories and centres

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

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

Agree

b) Improve access to patient groups, samples and data

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

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?

Creating a pan-European record of all the patients, with a standard structure, keeping it simple yet comprehensive

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

The security of many nationwide networks have been compromised so patients should not be able to be identified from this database

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

Smaller nations would not have 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

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

Question 2: Please rank the suggestions in order of priority

- First Priority
- 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)

Involving patients in research is the key to crack the problem. Researchers often don't meet, or don't want to meet patients, thinking that they have nothing to learn. Yet they do not know how these conditions affect patients.

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
1823
Title
Mrs
First Name
Diane
Surname
Robb
Category of respondee
Person with Parkinson's
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**
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?

Health and social care issues

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Conduct research into effects of nutrition and frailty

Second Priority

- f) Understand and investigate influence of comorbidities on NDD

Third Priority

- c) Research into the needs of carers

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Neutral

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

a) Increase involvement of individuals in research

Second Priority

f) Support for high-risk projects

Third Priority

c) Conduct multi-centre primary prevention studies

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

Information should be available to neurologists and parkinsons nurses to give to patients to decide. Research companies should reach out to patients instead of patients having to search for research projects/companies

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

Disagree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Disagree

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

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Disagree

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

Strongly Disagree

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

Agree

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?

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

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

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

b) Linking to treatment responses

Data, registries, repositories and centres

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

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

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

Disagree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

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?

each new diagnosed patient should be able to complete a standardised form relating to personal life/family history for general data and research purposes headed by hospital neurologists.

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Disagree

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

Strongly Agree

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

Strongly Agree

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

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

c) Facilitate research in areas outside university and hospital sectors

Second Priority

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

Third Priority

f) Review and update legislation on treatment

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

Funding and funding mechanisms

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

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

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

Second Priority

- a) Translational research needs to be promoted

Third Priority

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

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

Concluding questions

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

each patient should provide a detailed history of their life/family history for analysis to see if there are any comparing factors.

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

forms to be completed at hospital or through parkinsons support workers

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

register each newly diagnosed patient onto a data base and contact us directly asking us if we want to part of clinical trails.

UID
1825
Title
Mr
First Name
Colin
Surname
Hay
Category of respondee
Person with Parkinson's
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**
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?

- 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"**
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**
Agree
- e) **Rethink approaches to care**
Neutral
- 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**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

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

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

- 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?

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

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- g) Establish pan-European population-based studies

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Agree
- c) **Develop new biomarkers**
Neutral
- d) **Consider regulatory approaches**
Neutral

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

Data, registries, repositories and centres

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

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

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Disagree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

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

Neutral

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

Neutral

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Ensure greater engagement with regulators

Second Priority

Third Priority

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Neutral

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

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

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

Concluding questions

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

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

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

UID
1834
Title
Mr
First Name
Chris
Surname
Luckey
Category of respondee
Person with Parkinson's
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**
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?

- More Consultants needed

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**
Agree
- e) **Rethink approaches to care**
Agree
- f) **Understand and investigate influence of comorbidities**
Neutral
- g) **Conduct research into effects of nutrition and frailty**
Agree
- h) **Determine cost-effectiveness of healthcare pathways**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

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

Third Priority

- e) **Rethink approaches to care**

Question 3: How would you define "care"?

- Practical support for those in need

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- f) Support for high-risk projects

Third Priority

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**
- b) **Redefine and harmonise clinical endpoints and outcomes**
- c) **Develop new biomarkers**
- d) **Consider regulatory approaches**

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

Data, registries, repositories and centres

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

- a) **Improve access to, and sharing of, infrastructure and resources**
- b) **Improve access to patient groups, samples and data**
- c) **Improve data and sample collection**
- d) **Develop a register of persons with cognitive impairment**

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

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

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

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

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

d) Simplify funding application systems

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Concluding questions

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

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

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

UID

1839

Title

Mr

First Name

Richard

Surname

Brown

Category of respondee

Person with Parkinson's

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

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

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

e) Increase numbers of post-doctoral researchers

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

Biomarkers for early diagnosis

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

Agree

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

Strongly Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

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

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

provision of physical, emotional and financial support

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

Within the UK consistent provision of specialist Parkinson's nurses

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

Availability of suitable local respite care, free at the point of use

Prevention/treatment strategies and trials

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

- a) **Increase involvement of individuals in research**
Strongly Agree
- b) **Promote development of non-pharmacological interventions**
Neutral
- 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

- a) Increase involvement of individuals in research

Second Priority

- c) Conduct multi-centre primary prevention studies

Third Priority

- f) Support for high-risk projects

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

Better information, improved dissemination thro a range of media i eg email, press, TV

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?

Establish an accurate, broadly based database then concentrate efforts to identify biomarkers

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

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- d) Develop an improved understanding of the genetic basis

Third Priority

- a) Understand relationship between NDD and ageing

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

- c) Mechanisms of neuronal death and dysfunction

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

Sound risk assessment, fully explained to the participating patients and their carers

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?

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

Question 2: Please rank the suggestions in order of priority

First Priority

- 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?

- Common information technology standards, readily accessible

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

- Rigorous control of input organisations, then open access without risk of unauthorised input or changes to the approved data

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

- Generally no - but some risk that a strong, highly focussed centre of excellence might take too narrow a line of research

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**
Disagree
- 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

- d) Encourage industry to adopt pre-competitive approach

Third Priority

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

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

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

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

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

Third Priority

- d) Simplify funding application systems

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

Concluding questions

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

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

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

Consistent equality of treatment, care and infrastructure across the UK is vital

UID
1841
Title
Mrs
First Name
Joyce
Surname
De'Ath
Category of respondee
Person with Parkinson's
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**
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**
Neutral
- c) **Research into the needs of carers**
Agree
- d) **Research into care approaches including end of life decision-making**
Neutral
- e) **Rethink approaches to care**
Neutral
- f) **Understand and investigate influence of comorbidities**
Neutral
- g) **Conduct research into effects of nutrition and frailty**
Neutral
- h) **Determine cost-effectiveness of healthcare pathways**
Neutral

Question 2: Please rank the suggestions in order of priority

First Priority
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**
Agree

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

- e) Rethink approach to therapeutics

Second Priority

- f) Support for high-risk projects

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?

Need to ensure that potential participants and their doctors are aware of opportunities

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?

Drugs which are already used for other diseases eg exenatide as safety trials have already been done and therefore new treatments can be used more quickly

Disease cause, mechanisms and models

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

a) **Understand relationship between neurodegenerative disease and ageing**

Agree

b) **Improve understanding of disease stages**

Strongly Agree

c) **Improve understanding of disease mechanisms**

Agree

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

Agree

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

Agree

f) **Focus research on rare hereditary forms of disease**

Neutral

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

Strongly Agree

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

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

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

Not sure. Research should be judged on likelihood of success of development of potential treatments and on speed of developments

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**

Strongly Agree

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

Agree

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

- e) **Develop centres of excellence**

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

- e) **Develop centres of excellence**

Third Priority

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

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

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

Need to ensure research into varying pathways and not be wedded to one approach

Policy, regulation and legislation

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

- a) **Need for evidence-based policy**

Strongly Agree

- b) **Ensure greater engagement with regulators**

Strongly Agree

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

Agree

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

Strongly Agree

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

Strongly Agree

- f) **Review and update legislation on treatment**

Agree

- g) **Review and update legislation on privacy and data disclosure**

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- d) **Encourage industry to adopt pre-competitive approach**

Second Priority

- b) **Ensure greater engagement with regulators**

Third Priority

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

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

Funding and funding mechanisms

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

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

Strongly Agree

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

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

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?

UID
1842
Title
Mr
First Name
Richard
Surname
Windle
Category of respondee
Person with Parkinson's
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**
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**
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**
Neutral
- h) **Determine cost-effectiveness of healthcare pathways**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Research into the needs of carers

Second Priority

- d) Research end of life decision making

Third Priority

- e) Rethink approaches to care

Question 3: How would you define "care"?

Meeting the physical and emotional needs of the sufferer.

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?

Provide more support to carers so that patients are able to remain at home for longer.

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- d) Ensure better patient selection/stratification

Third Priority

- 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?

Set up a database of people with the condition who are willing to take part in research. This happens in the US and it is a shame there is nothing similar in the UK.

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**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

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

No. Research should be speeded up, but not at the expense of safety.

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

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

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

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

e) Develop centres of excellence

Third Priority

b) Improve access to patient groups, samples and data

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

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

Data should be open access. If privacy laws prevent this they should be changed.

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

May deter some researchers in other institutions from carrying out research in this area.

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

Neutral

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

Neutral

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

Neutral

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

b) Ensure greater engagement with regulators

Third Priority

g) Review and update legislation on privacy and data disclosure

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Neutral

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

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Encourage open-access sharing of data and materials

Second Priority

a) Translational research needs to be promoted

Third Priority

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)

No.

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

1846

Title

Drs

First Name

Flora

Surname

Hill

Category of respondee

Carer for person with Parkinson's

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

Neutral

d) Increase training for translational and clinician-scientists

Neutral

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?

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?

Education of patients should be promoted to improve the effectiveness of the treatment, and to allow better interaction between the patient and the medical staff. Patients should learn about the action of the medication prescribed. This would include: - effects and side effects of each individual medicine - dosage and timing - possible interaction between medicines and food and drink - possible effects of activity level/ exercise on effect of medication

Health and social care issues

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

a) Define the term "care"

Neutral

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

Neutral

c) Research into the needs of carers

Neutral

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

Neutral

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

g) Conduct research into effects of nutrition and frailty

Second Priority

f) Understand and investigate influence of comorbidities on NDD

Third Priority

e) Rethink approaches to care

Question 3: How would you define "care"?

Care is responding to the needs of the patient

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

Long term progressive conditions require continuity of care. The patient should be seen by the same person (consultant/ specialist nurse/ GP) at each visit. Care should include early referral to additional

therapeutic treatment (such as physiotherapy, speech and language therapy, occupational therapy) that will help the patient to live better with the condition and allow the patient to be independent for longer. For possible complications later in the course of the illness patients should be referred to consultants who have experience with the medical condition of the 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?

The advantage of home care can be improved by ensuring that the carer can leave the patient safely at home/ has sufficient respite care to allow a life without the progressive condition.

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

d) Ensure better patient selection/stratification

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

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?

By communication to people the results of the research work that is done with the help of courageous patients. (An example for Parkinson's disease are the fetal implants in patients in Sweden, which showed that the main disease process (aggregation of alpha-synuclein) also affected the implanted fetal dopaminergic cells, and that Parkinson's is not just a disease of aging, but a protein aggregation condition.)

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?

A requirement for a primary prevention trial is that the disease process is sufficiently understood. There is increasing evidence that many NDD's are in fact protein aggregation disorders (Brundin 2011). Trials with the wrong model (Q10 for Parkinson's) fail. Understanding why proteins start to aggregate (lack of chaperones?) is a key requirement before a primary prevention trial can be successful. There is little research on the effects of chaperones in the diet on the prevalence of NDD's. (Mediterranean diet and Parkinson's?) Another requirement is the availability of a relevant bio-marker (for instance alpha-synuclein in saliva from Pd patients and controls)

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

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

Disagree

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

- 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

To date there are no animal models that are representative for Parkinson's disease in humans (aggregation of alpha-synuclein and loss of alpha-synuclein in the CSF and saliva.) Testing of possible compounds that may reduce the rate of progression of a neurological disease that have been proven to be safe for other conditions (such as the anti-inflammatory drug Ibuprofen) could be done in patients. There is epidemiological evidence that people who use anti-inflammatory drugs regularly have a reduced risk to develop Alzheimer's or Parkinson's.

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

Neutral

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

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Disagree

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Improve data and sample collection

Second Priority

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

Third Priority

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

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

Sharing of data only adds value if the conditions under which the data have been acquired are well defined and known to all users. Agreed protocols for data acquisition are required to make data sharing a worthwhile activity.

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

See above.

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

So called 'centres of excellence' do not have to be the places where innovation originates. Who decides if a centre is excellent? Hopefully not the weight of the published papers.

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

Disagree

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

Disagree

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

Strongly Disagree

f) Review and update legislation on treatment

Strongly 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

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?

A promising treatment for the inflammation associated with NDD's is Ibuprofen. There are no incentives for industry and consultants (who often have relationships with pharmaceutical companies) to test Ibuprofen. This is a significant barrier to clinical trials. The industry tries to develop new anti-inflammatory drugs at great expense and little success. There is a role for the regulator to provide incentives to the consultants to conduct trials with medicines that are out of patent. The same applies to natural chaperones such as curcumin.

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Disagree

d) Simplify funding application systems

Neutral

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

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

Third Priority

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

Develop incentives for data sharing. Elaborate procedures could be a barrier to sharing.

Concluding questions

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

See previous answers. Trials of compounds, such as Ibuprofen, that could provide benefit for the patients, but are out of patent are not viable under the current system. If dietary chaperones are important for reducing the incidence of NDD's, these

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

The government has an interest to reduce the cost of treating patients with a NDD. It should provide the framework for a trial to investigate if Ibuprofen would slow down the progression of Pd after diagnosis. Although

the majority of patients with Parkinson's are diagnosed above the age of 65 years and have a relatively short duration of the disease (Ishihara 2007), the patients diagnosed below 65 form the majority of the patient community and live with the disease on average more than 20 years. For this group of patients a slight modification of the progression rate of the disease would have a significant benefit on quality of life and would reduce the care burden significantly. Part of the costs of such a trial could be raised from the patient community. The estimate of the number of patients with Parkinson's used to be some 120 000 in the UK and is being revised upwards based on a recent study. People living with somebody with Pd or knowing somebody with Pd realize how this condition takes one's life away very gradually. They would give generously to a trial that offered the prospect of a better life with Parkinson's. The research on chaperones is in its infancy. I would like to know if the food produced at an industrial scale (such as the strawberries or blueberries that look all right but taste of nothing) do still contain beneficial chaperones.

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

A very interesting initiative. My husband was diagnosed with Parkinson's more than 26 years ago. I am a physicist who had a career in the oil industry and learned the benefit of the integrated approach to oil and gas field development. This integration is clearly lacking in the world of medical research. Complex diseases like NDD's require an integrated approach to find better treatments.

UID

1847

Title

Mrs

First Name

Anne

Surname

Chatterley

Category of respondee

Carer for person with Parkinson's

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

Agree

d) Increase training for translational and clinician-scientists

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

Agree

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

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

d) Research end of life decision making

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Physical or emotional support which helps one stay as active and independent as possible

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

Be willing to help by providing small amounts of support rather than waiting until the family care breaks down

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

can be cheaper if professionals are willing to utilise family/friends. family need to be encouraged to assist in the care, need to advertise the positive aspects of caring rather than telling the family they will find it too difficult

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

Neutral

d) Ensure better patient selection/stratification

Disagree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

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?

Newspaper articles, magazines, approach tv/radio producers and encourage them to include characters who are thinking about taking part in research or organ donation. At the moment I m not aware of any adverts, articles or story lines outside of specialist publications. within the specialist publications have an occassional piece written by donors or those taking part in research on why they chose to do so.

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

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

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

Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

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

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

As a carer i think Animals are not humans and even after animal research the drugs sometimes have an unexpected effect on humans, all so time-consuming. If our condition is severe and we have had proper counselling I think we should be allowed to agree to participate if we so wish

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

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

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

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

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

Agree

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

Agree

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

Agree

f) Review and update legislation on treatment

Disagree

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

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Encourage open-access sharing of data and materials

Second Priority

d) Simplify funding application systems

Third Priority

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

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

Concluding questions

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

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

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

UID

1850

Title

The Very Revd Dr

First Name

Wesley

Surname

Carr

Category of respondee

Person with Parkinson's

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

Neutral

d) Increase training for translational and clinician-scientists

Neutral

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?

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"

Strongly Agree

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

Neutral

c) Research into the needs of carers

Neutral

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

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Disagree

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

Agree

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- 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?

no idea beyond the PD current programme

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

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- a) Understand relationship between NDD and ageing

Third Priority

- c) Improve understanding of disease mechanisms

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

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

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
Agree
- c) **Develop new biomarkers**
Neutral
- d) **Consider regulatory approaches**
Agree

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

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

Data, registries, repositories and centres

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

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

Neutral

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

Agree

- c) Improve data and sample collection

Neutral

- d) Develop a register of persons with cognitive impairment

Disagree

- e) Develop centres of excellence

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?

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

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

Policy, regulation and legislation

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

- a) Need for evidence-based policy

Agree

- b) Ensure greater engagement with regulators

Agree

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

Disagree

- 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

- b) Ensure greater engagement with regulators

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

Agree

- c) Joint academic-industry funding models

Neutral

- 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

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
1856
Title
Mrs
First Name
Pamela
Surname
Wells
Category of respondee
Person with Parkinson's
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**
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**
Neutral

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

Question 2: Please rank the suggestions in order of priority

First Priority

- d) **Research end of life decision making**

Second Priority

Third Priority

Question 3: How would you define "care"?

- being helped to feel that life is worth living

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 would like to know the answer !

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- b) Promote development of non-pharmacological interventions

Third Priority

- e) Rethink approach to therapeutics

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

- Advertise the need more widely

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 don't know

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

- 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?

- d) The biological basis of behavioural and psychological symptoms

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**
Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**
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?

b) Linking to treatment responses

Data, registries, repositories and centres

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

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

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Inaccessability for many patients

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

1858

Title

Mr

First Name

Derek

Surname

Lester

Category of respondee

Person with Parkinson's

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

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Agree

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

c) Increase overall numbers of researchers

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

Health and social care issues

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

a) Define the term "care"

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

c) Research into the needs of carers

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

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

Disagree

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

e) Rethink approach to therapeutics

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

More specific advertising aimed at people with NDD

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

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

- a) Redefine and standardise disease definitions and diagnosis
- b) Redefine and harmonise clinical endpoints and outcomes
- c) Develop new biomarkers
- d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

- First Priority**
- Second Priority**
- Third Priority**

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted**
- b) Encourage open-access sharing of data and materials**
- c) Joint academic-industry funding models**
- d) Simplify funding application systems**
- e) Maintain capacity for 'bottom-up' innovative funding**

Question 2: Please rank the suggestions in order of priority

- First Priority**
- Second Priority**
- Third Priority**

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

Concluding questions

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

It would appear that research is carried out at universities, hospitals and general research laboratories. A dedicated research facility for NDD would be more effective. (There probably is one)

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?

More emphasis should be placed on gene therapy Research into the physiological reasons of the varied effects of Levodopa deprivation, could lead to more effective control of the effects

UID
1862
Title
Mr
First Name
Ronald
Surname
Phillips
Category of respondee
Person with Parkinson's
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**
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?

Public Awareness of symptoms and drug side effects. too many stereotypes e.g. trembling parkinsons is misunderstood by the general public

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

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

- e) Rethink approaches to care

Question 3: How would you define "care"?

not something cost effective you cant put a price on it but the Tories do one for the rich and another for the poor

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

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

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

Third Priority

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

- more media public awareness to raise profile

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

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- a) Understand relationship between NDD and ageing

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

- d) The biological basis of behavioural and psychological symptoms

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

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

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

Data, registries, repositories and centres

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

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

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Develop a register of persons with cognitive impairment

Second Priority

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

Third Priority

b) Improve access to patient groups, samples and data

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Neutral

b) Ensure greater engagement with regulators

Agree

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

Agree

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

Neutral

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

Agree

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Facilitate research in areas outside university and hospital sectors

Second Priority

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

Third Priority

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

Funding and funding mechanisms

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

- a) **Translational research needs to be promoted**
Agree
- b) **Encourage open-access sharing of data and materials**
Agree
- c) **Joint academic-industry funding models**
Agree
- d) **Simplify funding application systems**
Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Translational research needs to be promoted

Second Priority

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

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
1865
Title
Mrs
First Name
Rosetta
Surname
Claxton
Category of respondee
Person with Parkinson's
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**
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**
- c) **Research into the needs of carers**
Agree
- d) **Research into care approaches including end of life decision-making**
- e) **Rethink approaches to care**
- f) **Understand and investigate influence of comorbidities**
- g) **Conduct research into effects of nutrition and frailty**
Agree
- h) **Determine cost-effectiveness of healthcare pathways**

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

- a) **Increase involvement of individuals in research**
Agree
- b) **Promote development of non-pharmacological interventions**
Neutral
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**

Neutral

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

b) Improve understanding of disease stages

c) Improve understanding of disease mechanisms

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

e) Determine the importance of genetic and environmental risk factors

f) Focus research on rare hereditary forms of disease

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

Agree

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

- a) **Need for evidence-based policy**
- 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**
Agree
- d) **Encourage industry to adopt a pre-competitive approach to research**
- e) **Rethink patent lifetime and conduct public-private clinical trials**
- f) **Review and update legislation on treatment**
- g) **Review and update legislation on privacy and data disclosure**

Question 2: Please rank the suggestions in order of priority

- First Priority**
- Second Priority**
- Third Priority**

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

Funding and funding mechanisms

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

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

I think that it would help all research if all the various charities that currently work independently of one and other, for instance ParkinsonsU.K. and the M.S.S. could pool some of their findings and save money .I am not a scientist but these diseases do seem to me to run on similar paths.

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

I am afraid not.I leave that to the experts.

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

Keep up trying to find cures for all these diseases so that the people following us will benefit from all you have discovered.

UID
1867
Title
Ms
First Name
Lia
Surname
Colacicco
Category of respondee
Person with Parkinson's
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**
Agree
- d) **Increase training for translational and clinician-scientists**
Neutral
- 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?

- 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?

Media dominated by alzheimers, v little on PD

Health and social care issues

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- f) Understand and investigate influence of comorbidities on NDD

Second Priority

- d) Research end of life decision making

Third Priority

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

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

d) Ensure better patient selection/stratification

Third Priority

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

Via the Parkinson magazine. ATM it feels like an exclusive club and I,m not important enough to join. The criteria are often not clear.

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

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

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

e) Determine the importance of genetic and environmental risk factors

f) Focus research on rare hereditary forms of disease

Strongly Disagree

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

b) Improve access to patient groups, samples and data

- c) Improve data and sample collection
- d) Develop a register of persons with cognitive impairment
- e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted
- b) Encourage open-access sharing of data and materials
- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Concluding questions

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

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?

[Do more research on coQ10 and make it available on prescription.](#)

UID
1868
Title
Mr
First Name
John
Surname
Lillywhite
Category of respondee
Person with Parkinson's
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**
Neutral
- d) **Increase training for translational and clinician-scientists**
Agree
- e) **Increase numbers of post-doctoral level researchers**
Agree

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

- a) Improve dialogue between researchers and wider population

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Rethink approaches to care

Second Priority

- c) Research into the needs of carers

Third Priority

- g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Recognition of the character and extent of the needs of the subject person and subsequent attention to them according to their seriousness.

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

Improved targeted publicity to reach those with needs.

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

Better provision of medical and non-medical support workers

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**
Neutral
- 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

- e) Rethink approach to therapeutics

Second Priority

- b) Promote development of non-pharmacological interventions

Third Priority

- d) Ensure better patient selection/stratification

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

By publicising results of studies, showing how a study increases the stock of knowledge from which treatments are derived

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**
Neutral
- e) **Determine the importance of genetic and environmental risk factors**
Agree
- f) **Focus research on rare hereditary forms of disease**
Disagree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Neutral
- h) **Develop more representative animal and cell-based models of disease**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Understand relationship between NDD and ageing

Second Priority

- 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?

- c) Mechanisms of neuronal death and dysfunction

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

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Disagree

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

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

Data, registries, repositories and centres

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

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

Neutral

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Disagree

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 foresee difficulties, how can we overcome these?

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

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

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

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

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

d) Simplify funding application systems

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Concluding questions

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

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

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

UID
1869
Title
Dr
First Name
Geoff
Surname
Butcher
Category of respondee
Person with Parkinson's
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**
Agree
- c) **Increase numbers of neurodegenerative disease (NDD) researchers**
Neutral
- d) **Increase training for translational and clinician-scientists**
Strongly Agree
- e) **Increase numbers of post-doctoral level researchers**
Strongly Agree

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

- e) Increase numbers of post-doctoral researchers

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

Health and social care issues

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Conduct research into effects of nutrition and frailty

Second Priority

- f) Understand and investigate influence of comorbidities on NDD

Third Priority

- d) Research end of life decision making

Question 3: How would you define "care"?

- Giving physical and emotional support to patient in accordance with their needs

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

- No experience of "care systems";

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

- No experience of "care systems";

Prevention/treatment strategies and trials

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

- a) **Increase involvement of individuals in research**
Agree
- b) **Promote development of non-pharmacological interventions**
Neutral
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
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

- c) Conduct multi-centre primary prevention studies

Second Priority

- a) Increase involvement of individuals in research

Third Priority

- f) Support for high-risk projects

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

- Advertising using internet, cinemas, shops etc

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?

- Possibly more genetic studies, epidemiology, and use of animal models - especially primates as few centres for these.

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

- 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?

- b) Neuronal inflammation

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

- I would regard missing out animal models as very unwise. My experience (in other fields) is that results from in vitro systems are often not reproducible in vivo.

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

Neutral

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

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

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?

Usual methods of open access journals

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

Traditional intellectual property rules that inhibit sharing data because of patents could perhaps be re-examined. There will always be some scientists who will keep critical bits of data to themselves to stay ahead of the field or employ other tricks – “its no good dreaming of systems so perfect that no one will need to be good”; [TS Eliot]

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

No - they already exist for some subjects

Policy, regulation and legislation

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

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

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

Neutral

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

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

d) Encourage industry to adopt pre-competitive approach

Third Priority

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

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

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

d) Simplify funding application systems

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

Should be a condition of getting funds

Concluding questions

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

You seem to have covered the most important aspects of the problem

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

Do not know enough of the field generally to comment

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

I have previously suggested more research on inflammation and possibility of critical role of TNF This does seem a major influence in a wide variety of diseases

UID

1879

Title

Mrs

First Name

Ann

Surname

Straker

Category of respondee

Person with Parkinson's

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

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

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

c) Increase overall numbers of researchers

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

Health and social care issues

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

a) Define the term "care"

Agree

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

Neutral

c) Research into the needs of carers

Agree

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

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

e) Rethink approaches to care

Third Priority

d) Research end of life decision making

Question 3: How would you define "care"?

Definition of the help required at different stages of the patients illness.

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

On the lines of MacMillan nurses perhaps.

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

More peripatetic nurses, who are specialised in the patient's specific illness.

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- d) Ensure better patient selection/stratification

Third Priority

- e) Rethink approach to therapeutics

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

- Make use of all media to ensure people know about the opportunities for donating brain material.

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

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

- a) **Redefine and standardise disease definitions and diagnosis**
- b) **Redefine and harmonise clinical endpoints and outcomes**
- c) **Develop new biomarkers**
- d) **Consider regulatory approaches**

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

Data, registries, repositories and centres

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

- a) **Improve access to, and sharing of, infrastructure and resources**
- b) **Improve access to patient groups, samples and data**

- c) Improve data and sample collection
- d) Develop a register of persons with cognitive impairment
- e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted
- b) Encourage open-access sharing of data and materials
- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Concluding questions

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

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

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

UID
1880
Title
Mrs
First Name
Ann
Surname
Dinnage
Category of respondee
Person with Parkinson's
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?

A need to find new cures and medicines to assist sufferer's symptoms

Health and social care issues

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

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

- c) Research into the needs of carers

Third Priority

- e) Rethink approaches to care

Question 3: How would you define "care"?

managing the well being and safety of the patient to enable them to lead as independent a life as possible

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

There needs to be more information about what care is available and how to access such care. Current local authority cuts means that local authorities are not actively promoting their services and in many instances may actually be 'concealing'; services and being evasive to applicants. There need to be national minimum standards of provision and a clear allocation of responsibility to providers to make services available to those in need and not just those 'in the know'

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

There needs to be more support for caring in the home for those that need it, and it needs to be based on the patient and primary carers ability to manage and their needs, be they financial or otherwise. Current services are based on the ability of providers to respond and not on the needs of carers. There could be some scope for voluntary and community based support so long as it was additional to proper professional provision and not instead of it. Schemes may exist but are not well publicised

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

- b) Promote development of non-pharmacological interventions

Third Priority

- e) Rethink approach to therapeutics

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

There is a need to explain the benefits and highlight discoveries which have been made through research and donations

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?

You need to rephrase this question, (and some of the others) in plain English. Then you might get some more useful answers

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**
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?

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 comment](#)

Diagnosis, disease definitions and outcome measures

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

- a) Redefine and standardise disease definitions and diagnosis
- b) Redefine and harmonise clinical endpoints and outcomes
- c) Develop new biomarkers
- d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted
[Strongly Agree](#)
- b) Encourage open-access sharing of data and materials
[Strongly Agree](#)
- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

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

Concluding questions

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

No

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

No

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

There is a need for research to be coordinated and for practitioners, relevant healthcare professionals, patients and carers to be kept in touch with progress. The Parkinson's Society is pretty good at keeping me informed, but often the local providers are not aware of the assistance on offer.

UID
1884
Title
Mr
First Name
Ivor
Surname
Hillman
Category of respondee
Person with Parkinson's
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**
Agree
- d) **Increase training for translational and clinician-scientists**
Strongly Agree
- e) **Increase numbers of post-doctoral level researchers**
Strongly Agree

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

- c) Increase overall numbers of researchers

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

Health and social care issues

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Research into the needs of carers

Second Priority

- e) Rethink approaches to care

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**

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

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

f) Support for high-risk projects

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

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

Recruit more patients. Many really want to do this despite the risks, feeling what have they got to lose?

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

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

Agree

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

b) Improve understanding of disease stages

Second Priority

a) Understand relationship between NDD and ageing

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**
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**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

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

Third Priority

- d) Develop a register of persons with cognitive impairment

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Funding and funding mechanisms

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

- a) **Translational research needs to be promoted**
Agree
- b) **Encourage open-access sharing of data and materials**
Agree
- c) **Joint academic-industry funding models**
- d) **Simplify funding application systems**
Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

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
1885
Title
Mr
First Name
Ian
Surname
Johnstone
Category of respondee
Person with Parkinson's
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**
Agree
- d) **Increase training for translational and clinician-scientists**
Agree
- e) **Increase numbers of post-doctoral level researchers**
Strongly Agree

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

- 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?

Public awareness regarding status of research activities. This may just be a problem with the Fourth Estate but there is far too much 'hype' regarding research breakthroughs.

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**
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

- c) Research into the needs of carers

Question 3: How would you define "care"?

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

Do not centralise the responsibility and associated accountability - keep it small and keep it local. Specialist Parkinson's nurses are a fantastic resource acting as interface between the patient and the (sometimes distant) senior medical staff.

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 'packages' will be different for each and every sufferer so two-way discussion is required for each case.

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Disagree

e) Rethink approach to therapeutics

Strongly Disagree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

f) Support for high-risk projects

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?

When I was diagnosed the first priority was to determine a good treatment regime, however the RSN (Research Support Network) and Brain Bank were never mentioned once. Maybe more effort could be applied to the promotion of these two key areas?

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

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

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

d) Develop an improved understanding of the genetic basis

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

This would work as long as the cell-based model could be shown to be representative of the, if you like, bulk human or complete brain.

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

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

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

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

e) Develop centres of excellence

Third Priority

c) Improve data and sample collection

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

Use of modern communications technology. Academics already use the internet widely but there can be problems regarding information publication prior to Peer Review. A mechanism must be found to speed up the Peer Review process.

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

Open Access is all well and good for publicly funded academic (ie university) research but it might prove difficult for industrial researchers where share price is usually intimately linked to the success or failure of a clinical trial. A possible way around the above problem would be to offer some type of accreditation to the industrial researcher thereby protecting any future profits made, for example, from drug sales. How this would translate across borders is difficult to imagine knowing how fond the Indians and Chinese are of trying to break drug patents. Maybe they could be involved in the research thereby 'tying' them in.

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

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

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

a) Need for evidence-based policy

Second Priority

b) Ensure greater engagement with regulators

Third Priority

c) Facilitate research in areas outside university and hospital sectors

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

Put measures in place that would prevent future governments blocking or banning stem cell research on religious grounds. Move R&D into a secular environment.

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Joint academic-industry funding models

Second Priority

c) Joint academic-industry funding models

Third Priority

d) Simplify funding application systems

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

Concluding questions

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

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

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

UID
1888
Title
Mrs
First Name
Alison
Surname
Hughes
Category of respondee
Person with Parkinson's
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?

- b) Improve education and training of healthcare professionals

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

I believe that GPs need up to date training in order to be able to deliver a high and consistent level of care to both their patients and carers, and in turn transfer their knowledge to non clinical workers eg receptionists etc. All surgeries should have a trained liason officer who would be at hand to help with any concerns. PS I am also a nursing sister at my local hospital - During the last three years i have been discriminated against due to my disability.

Health and social care issues

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

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

- c) Research into the needs of carers

Third Priority

- d) Research end of life decision making

Question 3: How would you define "care"?

Care is meeting the needs of the individual eg physical, emotional and financial in order that they can lead a high quality of life with dignity and the feeling that they are the most important person in the world.

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

GPS need to be kept up to date to provide better service to their patients. They have to be better structured on the prescription of medication i.e. to prevent mismanagement of drugs and to provide people with more information on how to manage their medication.

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

Consistent team of 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

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Ensure better patient selection/stratification

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?

promote the research - PD is still seen as an old person's disease. I developed the condition when I was forty eight years ago.

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?

Promotion of the scheme

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

Neutral

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

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

Neutral

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

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

Agree

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

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve understanding of disease stages

Second Priority

h) Develop more representative animal and cell-based models

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?

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

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Agree

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

b) Linking to treatment responses

Data, registries, repositories and centres

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

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

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

e) Develop centres of excellence

Third Priority

c) Improve data and sample collection

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

media promotion of register Gps must be involved

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

Invades privacy communication essential to promote research

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

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

Strongly Agree

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

Strongly Agree

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

Strongly Agree

f) Review and update legislation on treatment

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

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

Second Priority

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

Third Priority

- a) Need for evidence-based policy

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

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

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

- d) Simplify funding application systems

Third Priority

- a) Translational research needs to be promoted

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

Concluding questions

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

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

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

UID
1898
Title
Mrs
First Name
Mary
Surname
Jones
Category of respondee
Person with Parkinson's
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**
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?

More DNA analysis and interaction of researchers of separate neuro-related tests.

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**
Disagree
- 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

Third Priority

Question 3: How would you define "care"?

A line of approach from patient to carer to specialist and vice versa, without the red-tape and delays presently incurred. Worry and apprehension do not help patient or carer.

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

Contact between patient/carers and authorities to be instigated by the authority on a monthly continuous system.

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

Easy prompt access to manual and mental aides. Also descriptive literature as a back-up to list facilities available for that area.

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Increase involvement of individuals in research

Second Priority

Third Priority

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

If a large amount of travel was not involved and if patients were told the purpose and result of their participation in the 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?

Continuation of present trials but multi-centres covering neurological diseases internationally.

Disease cause, mechanisms and models

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

- a) **Understand relationship between neurodegenerative disease and ageing**
Disagree
- b) **Improve understanding of disease stages**
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**
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

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

Second Priority

Third Priority

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

- b) Neuronal inflammation

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

If proved safe for a different neuro disease, miss out tests on animals and have trials for patients if they so request.

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

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

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

Third Priority

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

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

Profit makers in the medication firms will always put profit first and would not wish to share research especially side effects. Cannot be overcome whilst greedy share holders are around.

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

Research techniques would benefit but some may not be as safe as the limitations required in this country.

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
1926
Title
Mrs
First Name
Mary
Surname
Brightwell
Category of respondee
Person with Parkinson's
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?

Health and social care issues

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Rethink approaches to care

Second Priority

- c) Research into the needs of carers

Third Priority

- d) Research end of life decision making

Question 3: How would you define "care"?

Responding to the needs of the patient and working closely to implement their decisions

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

All aspects of care communicating i.e. doctors,nurses,relatives, immediate carers, social workers

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

Respite for the carer so the patient does not feel guilt.

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- d) Ensure better patient selection/stratification

Second Priority

- e) Rethink approach to therapeutics

Third Priority

- c) Conduct multi-centre primary prevention studies

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

- Through consultants/Gps

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?

- Don't understand

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- g) Establish pan-European population-based studies

Second Priority

- c) Improve understanding of disease mechanisms

Third Priority

- b) Improve understanding of disease stages

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

- 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
- b) Redefine and harmonise clinical endpoints and outcomes
- c) Develop new biomarkers
- d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted
- b) Encourage open-access sharing of data and materials
- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Concluding questions

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

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

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

UID

1933

Title

Mrs

First Name

Lesley

Surname

Howett

Category of respondee

Person with Parkinson's

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?

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"

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

c) Research into the needs of carers

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

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

Second Priority

e) Rethink approach to therapeutics

Third Priority

a) Increase involvement of individuals in research

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

information to encourage more people to take part should be widely publicised for example local gp surgeries, information needs to be given to people with ndd in term that can be easily understood.

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?

exercise

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

Diagnosis, disease definitions and outcome measures

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

- a) Redefine and standardise disease definitions and diagnosis
- b) Redefine and harmonise clinical endpoints and outcomes
- c) Develop new biomarkers
- d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted**
- b) Encourage open-access sharing of data and materials**
- c) Joint academic-industry funding models**
- d) Simplify funding application systems**
- e) Maintain capacity for 'bottom-up' innovative funding**

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

Concluding questions

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

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

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

UID
1936
Title
Mrs
First Name
Carol
Surname
Vaughton
Category of respondee
Person with Parkinson's
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?

Health and social care issues

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

- a) **Define the term "care"**
Strongly Agree
- b) **Survey long-term care standards and provision across Europe**
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**
Strongly Agree
- f) **Understand and investigate influence of comorbidities**
Agree
- g) **Conduct research into effects of nutrition and frailty**
Strongly Agree
- h) **Determine cost-effectiveness of healthcare pathways**
Neutral

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

- g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Making safe and encouraging independence where possible removal of stigma

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

Removal of stigma attached to all neuro conditions

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

more relief for 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**
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

- d) Ensure better patient selection/stratification

Second Priority

- a) Increase involvement of individuals in research

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?

- Publicity in a wider range of media-including non medical

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?

- don't know

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Improve understanding of disease stages

Second Priority

- g) Establish pan-European population-based studies

Third Priority

- a) Understand relationship between NDD and ageing

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

- d) The biological basis of behavioural and psychological symptoms

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

- no

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

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

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

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

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

Strongly Agree

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

Strongly Agree

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

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
1939
Title
Mr
First Name
John
Surname
Massey
Category of respondee
Person with Parkinson's
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**
Agree
- d) **Increase training for translational and clinician-scientists**
Agree
- e) **Increase numbers of post-doctoral level researchers**
Agree

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

- a) **Improve dialogue between researchers and wider population**

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

Health and social care issues

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

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

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

Question 3: How would you define "care"?

treating others as you would expect them to treat you

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

wherever possible, care to be local or home based and seamless between providers-a one stop shop.

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

education, education and education

Prevention/treatment strategies and trials

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

- a) **Increase involvement of individuals in research**
Strongly Agree
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Agree
- d) **Ensure better patient selection/stratification**

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

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?

RESEARCH targeted personal approach to people identified by their consultant as being suitable. BRAIN DONATION regular persuasive appeals in target media

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?

investigate any link with diet and environmental factors

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

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

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

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

Strongly Agree

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

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

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?

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

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

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

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

Policy, regulation and legislation

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

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

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted
- b) Encourage open-access sharing of data and materials
- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

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

Concluding questions

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

[maximize utilisation of patients willingness to cooperate in any way to help beat these diseases](#)

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

[use of patient diaries, questionnaires, panels](#)

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

UID
1940
Title
Professor
First Name
Brian
Surname
Underwood
Category of respondee
Person with Parkinson's
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**
Agree
- c) **Increase numbers of neurodegenerative disease (NDD) researchers**
Strongly Agree
- d) **Increase training for translational and clinician-scientists**
Agree
- e) **Increase numbers of post-doctoral level researchers**
Strongly Agree

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

- c) Increase overall numbers of researchers

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

Health and social care issues

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

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

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

- f) Understand and investigate influence of comorbidities on NDD

Second Priority

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

Third Priority

- a) Define the term 'care'

Question 3: How would you define "care"?

Acceptance of the responsibility for someone one cares about.

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

No&t; I don't know enough about present systems.

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

Recognise that there is a cost.

Prevention/treatment strategies and trials

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- b) Promote development of non-pharmacological interventions

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?

- Make it more generally known that that is what is needed

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?

- There should be an emphasis on cure

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Understand relationship between NDD and ageing

Second Priority

- b) Improve understanding of disease stages

Third Priority

- c) Improve understanding of disease mechanisms

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

- c) Mechanisms of neuronal death and dysfunction

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

- Ask people with neuro-degenerative illness to participate

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?

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

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?

As in e) above > develop Centre of excellence

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

By making people aware of what one is doing.

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

No.

Policy, regulation and legislation

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

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

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

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

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

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?

No.

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Agree

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Encourage open-access sharing of data and materials

Second Priority

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?

UID

1966

Title

Mrs

First Name

Shirley

Surname

Rodwell

Category of respondee

Carer for person with Parkinson's

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?

e) Increase numbers of post-doctoral researchers

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

That early diagnosis can help the patient. Our doctor put his hand over my husband's shaking hand on his desk. When asked if he thought my husband had Parkinson's, the doctor replied 'It doesn't matter'. This was 3 years before it was officially diagnosed when he was in hospital.

Health and social care issues

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

Agree

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

Strongly Agree

c) Research into the needs of carers

Strongly Agree

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

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

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

g) Conduct research into effects of nutrition and frailty

Third Priority

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

Question 3: How would you define "care"?

Support provided to enable the patient to survive with the least amount of discomfort and depression.

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

The GP sends the patient off to see a hospital specialist (sometimes waiting months for a consultation) every time the patient indicates a new/different symptom. As there is no central reporting system, the results of investigations are available neither to the GP who is not particularly interested anyway nor any of the

consultants. Result no joined-up diagnosis. GPs tend not to read the letters sent from the consultants until he has to answer a question from the patient. Often advice to change medication is not included in the prescription list for several weeks. Much of the necessary knowledge about a patient is reported by the patient/carer to the consultant. The less articulate clearly lose out.

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

We only know about care at home. What I heard about the social services method of sending someone in to the home three times a day, had a very bad reputation. I therefore decided what is euphemistically referred to as 'A Private Care Package' which means that no-one follows through contact with the patient. Everything falls on the family carer and the assistance she can afford.

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

e) Rethink approach to therapeutics

Third Priority

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?

Educating the public, first through Parkinson's club members, then with Dept. of Health support, though publicity in surgeries

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?

Gather supporters through GPs and medical centres

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

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

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Strongly Agree

f) Focus research on rare hereditary forms of disease

Neutral

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

Strongly Agree

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

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve understanding of disease stages

Second Priority

d) Develop an improved understanding of the genetic basis

Third Priority

g) Establish pan-European population-based studies

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

c) Mechanisms of neuronal death and dysfunction

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

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Strongly Agree

d) Consider regulatory approaches

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

c) Improve data and sample collection

Second Priority

e) Develop centres of excellence

Third Priority

b) Improve access to patient groups, samples and data

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

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

2000

Title

Mr

First Name

Anthony

Surname

Wells

Category of respondee

Person with Parkinson's

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

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

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

b) Improve education and training of healthcare professionals

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

RNA,DNA.DIET, ENVIREAMENT.CAUSES.EARLY DIAGNOSIS.TREATMENT. GENETIC AND PROTEIN BEHAVIOR.

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

Agree

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

Strongly Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

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

g) Conduct research into effects of nutrition and frailty

Third Priority

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

Question 3: How would you define "care"?

RECONIZING WEAKNESS, TOP NEEDS FOR PATIENTS SUCH AS ABILITY TO DRESS, EAT, REMEMBER MEDICATION ON TIME. AWARENESS FROM THE PUBLIC ABOUT THE CONDITION. RELIEVING UNDUE STRESS. PROPER MEALS WELL BALANCED. SOCIAL SERVICES. CONSULTANT AND PD NURSE HELP.

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

SOCIAL SERVICE HELP. MORE PD NURSE CARE. TRAINING CARERS. REMEMBER FAMILY CARERS MAY ALSO HAVE PROBLEMS WITH HEALTH. Family kept in touch.

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

advantages of hospital are on the spot treatment. food and medication instantly available. professional doctors and nurses available. All costly. and bigger facilities needed' sometimes more stressful and lack of communication. Being at home can be less stressful and less travelling for patients and carers. PD nurses could visit quicker than seeing doctor then consultant. Less costly.

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

Second Priority

a) Increase involvement of individuals in research

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?

advertise doctors surgeries, hospitals, visiting schools.

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?

YES. DNA BETTER RESEARCH INTO CAUSES. HIGHLY SKILLED CONSULTANTS EARLY DIAGNOSIS.

Disease cause, mechanisms and models

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

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Agree

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

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

a) Understand relationship between NDD and ageing

Second Priority

e) Determine the importance of genetic and environmental risk factors

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

DO NOT AGREE.

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Strongly Agree

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

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

Data, registries, repositories and centres

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

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

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

Strongly Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

Second Priority

c) Improve data and sample collection

Third Priority

c) Improve data and sample collection

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

SKYPE.MEETINGS PUBLICITY,

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

General world wide Data banks esseseable to top scientices and consultants

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

Not unless disease could develop and spread.

Policy, regulation and legislation

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

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Strongly Agree

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

Strongly Agree

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

Strongly Agree

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

Strongly Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

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

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?

global cooperation. trust amongst civilised governments.

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

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

d) Simplify funding application systems

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

vetting of institutions involved.

Concluding questions

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

PUBLIC VEIWS. AS YOU ARE DOING IN THIS SERVEY.

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

ENCOURAGE PEOPLE TO TAKE PART.

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

KEEP EVERYONE FOCASED AND INVOLVED.

UID

1837

Title

Mrs

First Name

Helen

Surname

McBean

Category of respondee

Person with Parkinson's

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

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

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

c) Increase overall numbers of researchers

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

Health and social care issues

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

a) Define the term "care"

Agree

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

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

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Conduct research into effects of nutrition and frailty

Second Priority

h) Determine cost-effectiveness of healthcare pathways

Third Priority

d) Research end of life decision making

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Ensure better patient selection/stratification

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

f) Support for high-risk projects

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

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

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

Neutral

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Strongly Agree

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

Agree

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

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve understanding of disease stages

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

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?

b) Neuronal inflammation

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

Diagnosis, disease definitions and outcome measures

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

a) Redefine and standardise disease definitions and diagnosis

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?

d) Facilitating back-translation to models of disease

Data, registries, repositories and centres

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

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

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve data and sample collection

Second Priority

e) Develop centres of excellence

Third Priority

b) Improve access to patient groups, samples and data

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Strongly Agree

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

Strongly Agree

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

Agree

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

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Need for evidence-based policy

Second Priority

f) Review and update legislation on treatment

Third Priority

b) Ensure greater engagement with regulators

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

Funding and funding mechanisms

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

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

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

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

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

Third Priority

d) Simplify funding application systems

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

Concluding questions

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

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 respondent

Carer for person with Parkinson's

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

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?

yes , patients should be treated holistically, with as much emphasis on treating related issues which can feed into increasing the symptoms of Parkinsons

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

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

e) Rethink approaches to care

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

giving either and or emotional and physical support. Emotional support can be more draining than coping with physical needs

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

giving more support for carers and recognising that if patients stay in their own homes carers need resources put into looking after their own well being.

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

Support for carers to enable them to cope and stay strong. If they succumb to ill health everyone loses.

Prevention/treatment strategies and trials**Question 1: Please indicate to what extent you endorse the following points**

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

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approach to therapeutics

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

b) Promote development of non-pharmacological interventions

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

education and information

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

dont know

Disease cause, mechanisms and models

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

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

Question 2: Please rank the suggestions in order of priority

First Priority

h) Develop more representative animal and cell-based models

Second Priority

a) Understand relationship between NDD and ageing

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

No I do not think this would 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

Agree

d) Consider regulatory approaches

Neutral

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

b) Linking to treatment responses

Data, registries, repositories and centres

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

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

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Agree

d) Develop a register of persons with cognitive impairment

Neutral

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

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

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

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

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

Policy, regulation and legislation

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

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

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

Strongly Agree

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

Agree

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

Agree

f) Review and update legislation on treatment

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

a) Need for evidence-based policy

Third Priority

f) Review and update legislation on treatment

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

Funding and funding mechanisms

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

- a) Translational research needs to be promoted
- 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

1811

Category of respondee

Person with Parkinson's

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

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?

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?

More research into the speed of the progression of the the disease which varies greatly.

Health and social care issues

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

a) Define the term "care"

Agree

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

Neutral

c) Research into the needs of carers

Agree

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

Agree

e) Rethink approaches to care

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

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"?

helping a person to cope with their disability while leading as normal a life as possible.

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

the main problem seems to be providing care to a disabled person living alone. Care provision should give them priority.

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

comparative study of the costs of care at home and in residential care would help to identify the areas where it could be managed more efficiently.

Prevention/treatment strategies and trials

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

- a) **Increase involvement of individuals in research**
Agree
- b) **Promote development of non-pharmacological interventions**
Neutral
- c) **Conduct multi-centre primary prevention studies**
Strongly Agree
- d) **Ensure better patient selection/stratification**
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

- d) Ensure better patient selection/stratification

Third Priority

- a) Increase involvement of individuals in research

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

we should all promote interest via this web site , publications and local branch activities.

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 don't know

Disease cause, mechanisms and models

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

- a) **Understand relationship between neurodegenerative disease and ageing**
Strongly Agree
- b) **Improve understanding of disease stages**
Strongly Agree
- c) **Improve understanding of disease mechanisms**
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
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

Second Priority

Third Priority

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

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**
- b) **Redefine and harmonise clinical endpoints and outcomes**
- c) **Develop new biomarkers**
- d) **Consider regulatory approaches**

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) Improve access to, and sharing of, infrastructure and resources
- b) Improve access to patient groups, samples and data
- c) Improve data and sample collection
- d) Develop a register of persons with cognitive impairment
- e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) Need for evidence-based policy
- b) Ensure greater engagement with regulators
- c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
- d) Encourage industry to adopt a pre-competitive approach to research
- e) Rethink patent lifetime and conduct public-private clinical trials
- f) Review and update legislation on treatment
- g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted
- b) Encourage open-access sharing of data and materials
- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

- First Priority
- Second Priority
- Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1813

Category of respondee

Person with Parkinson's

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

Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

yes! Parkinson's is the poor relation of neurological disorders and needs to raise its profile by a constant PR campaign highlight the day to day impact it has on 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

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Define the term "care"

Second Priority

b) Survey long-term care standards and provision across Europe

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

looking after someone at the same time ensuring they have dignity and independence as much as possible be allowed

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

b) Promote development of non-pharmacological interventions

Third Priority

e) Rethink approach to therapeutics

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

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

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Understand relationship between NDD and ageing

Second Priority

c) Improve understanding of disease mechanisms

Third Priority

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

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

- a) Improve access to, and sharing of, infrastructure and resources
- b) Improve access to patient groups, samples and data
- c) Improve data and sample collection
- d) Develop a register of persons with cognitive impairment
- e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

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)

Patient input seems to be seriously lacking!

Question 2: Do you have any comments on how to implement the above suggestion(s)?

By monitoring patients and their progress

Question 3: Is there anything else you would like to tell us?

UID

1820

Category of respondent

Patient with a neurodegenerative condition or their carer

Country

United Kingdom

Are you a patient with a neurodegenerative condition or a carer?

Patient

Type

Person with Parkinson's

Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Strongly Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

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

Neutral

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

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

g) Conduct research into effects of nutrition and frailty

Second Priority

f) Understand and investigate influence of comorbidities on NDD

Third Priority

c) Research into the needs of carers

Question 3: How would you define "care"?

The systems in place to support the patient so that they can live as normal a life as they did before having the illness

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

It should not be up to the patient to work out who is supposed to help with a particular issue or how they are supposed to address a problem. GPs should be at the heart of care for the patient and it should be for them, or their practice, to signpost and navigate the way through the various care and support systems including financial support.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Neutral
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Neutral
- 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

- d) Ensure better patient selection/stratification

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?

Provide some system or assurance that if they benefit from the trial treatment they can continue to receive it. The story of the aborted GDNF trial was enough to put me off participating in drug trials while I am still trying to hold down employment.

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**
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**
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

- f) Focus research on rare hereditary forms of disease

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

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?

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

Neutral

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

b) Improve access to patient groups, samples and data

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

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)

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

1828

Category of respondee

Person with Parkinson's

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

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

Agree

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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"?

care is the activity of looking after the general wellbeing of a sufferer including the understanding of their particular problems and ways of helping them through the difficulties which undoubtedly occur

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?

assist the healthcare authorities with the issues of providing more home support and also assist the patient with suggestions to any modifications to their lifestyle etc

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Neutral

d) Ensure better patient selection/stratification

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

d) Ensure better patient selection/stratification

Third Priority

b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Strongly Agree

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Neutral

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Agree

h) Develop more representative animal and cell-based models of disease

Disagree

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

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

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

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

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?

better cooperation between the various disease research groups

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

not comfortable with the data being widely available due to the increased incidence of hacking. improve greatly the 'firewall'; protection

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

not really, however please see answer to question 4

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Review and update legislation on privacy and data disclosure

Second Priority

c) Facilitate research in areas outside university and hospital sectors

Third Priority

e) Rethink patent lifetime and conduct public-private clinical trials

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) **Translational research needs to be promoted**
Agree
- b) **Encourage open-access sharing of data and materials**
Neutral
- 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

- d) Simplify funding application systems

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

1845

Category of respondee

Person with Parkinson's

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

Agree

d) Increase training for translational and clinician-scientists

Strongly Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

d) Increase training for translational and clinician-scientists

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Communication and exchange of ideas within and between the research science and clinical community, as well as between both these groups and those working in less directly related disciplines is incredibly important. So many important steps forward are the result of cross-fertilisation and chance encounters/conversations with individuals who perhaps have a fresh approach to a problem because they come from a very different environment.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Disagree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Conduct multi-centre primary prevention studies

Second Priority

- a) Increase involvement of individuals in research

Third Priority

- b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

1. Taking part in research: Increase understanding of how important this is through promotional education . Enrol people when they attend for a clinic appointment, where they can speak to someone face to face and also have hopefully just been helped themselves and therefore may be more prepared to help with research in exchange.

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

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Improve understanding of disease mechanisms

Second Priority

- a) Understand relationship between NDD and ageing

Third Priority

- e) Determine the importance of genetic and environmental risk factors

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

If people are willing to take the risk, I see no reason why this should not happen. Obviously those agreeing to take part would have to be very carefully counselled to ensure they appreciated the implications of what they were agreeing to. Animal models may be unreliable or unrepresentative of some human characteristics so there is always some risk , even when animal models are used to test a new treatment.

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

Strongly Agree

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

Strongly Agree

- e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) Need for evidence-based policy
- b) Ensure greater engagement with regulators
- c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community
- d) Encourage industry to adopt a pre-competitive approach to research
- e) Rethink patent lifetime and conduct public-private clinical trials
- f) Review and update legislation on treatment
- g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted
- 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
 - 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)

Patient groups eg support groups and local branches are a potent source of research participants and fundraising for research. Sending out research representatives to explain what is being done and why and how people could help is like to generate a positive response in most such groups.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

This could be done via the charity eg Parkinson's UK.

Question 3: Is there anything else you would like to tell us?

UID

1848

Category of respondee

Person with Parkinson's

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

Agree

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

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

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

a) Define the term "care"

Second Priority

e) Rethink approaches to care

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Disagree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

f) Support for high-risk projects

Third Priority

b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

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

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

a) Interactions between cells and their surrounding intra- and extracellular environment

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Neutral

c) Develop new biomarkers

Neutral

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Neutral

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Neutral

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

d) Simplify funding application systems

e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

The standards of diagnosis, treatment and patient relationship should be uniformly available throughout the UK etc.

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Databases available in all centres would ensure that available resources are accessible in all areas

Question 3: Is there anything else you would like to tell us?

UID

1860

Category of respondee

Person with Parkinson's

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

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

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

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Assistance with day-to-day living. This includes any aspect of dependance on another person, whether for food, mobility or personal hygiene. I currently 'care' for my two children (7 and 4). I do not currently need care, although I recognise that I probably will do one day.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

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?

Location of the research can be important. How likely is it that an individual would be prepared to travel 100 miles to participate in research? Some individuals find it difficult to travel or to spend time travelling (I, for example, need to factor in my young children's needs when considering such issues; I can only realistically spare the time that they are at school). Multi-centre research or even mobile research may be the answer, depending on the type of research. It occurs to me that centres of further education may be able to offer facilities in exchange for experience/observation of high level research techniques. Some smaller centres of higher education may also be willing to assist in taking research to the participants. I would welcome some sort of filtration process when I am notified of opportunities to participate in research; many of them are irrelevant to my situation. I'm not sure that opportunities to participate in research or brain donation are as well publicised as they might be. Does the brain bank have any links with the national blood service? A few well targeted leaflets may gain some healthy donors there.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Establish pan-European population-based studies

Second Priority

h) Develop more representative animal and cell-based models

Third Priority

c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

if the animal model is not considered reliable - if the cell-based model is considered to carry unusually high potential - if the mechanism is well understood and if theory links the cell-based model closely to what is known/believed to happen in the brain - if the risk to human subjects is deemed small - if the substance to be tested is already in use for another purpose - on the whole, I would prefer to avoid animal experimentation on the grounds of potential cruelty to the animals (not that I believe lab animals are deliberately treated badly), but I recognise that in some circumstances it cannot - and should not - be omitted from the standard research progression.

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Improve access to, and sharing of, infrastructure and resources

Second Priority

c) Improve data and sample collection

Third Priority

e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Neutral

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Strongly Agree

c) Joint academic-industry funding models

Strongly Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Joint academic-industry funding models

Second Priority

b) Encourage open-access sharing of data and materials

Third Priority

e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

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

1861

Category of respondee

Person with Parkinson's

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?

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

Agree

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Rethink approaches to care

Second Priority

b) Survey long-term care standards and provision across Europe

Third Priority

h) Determine cost-effectiveness of healthcare pathways

Question 3: How would you define "care"?

Anyone involved with person with a long term neurological disorder is providing some sort of care ie doctor, spouse, children, friend, work colleagues etc.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

There needs to be a much higher minimum standard of care for patients with neurological disorders. Doctors, nursing staff, etc in the care system need to have more training on neurological disorders so they have greater understanding of its devastating impact.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Patients would prefer to be cared for at home but need more support from outside carers coming in to help.

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

- b) Promote development of non-pharmacological interventions

Second Priority

- a) Increase involvement of individuals in research

Third Priority

- c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

- Advertise more through the media.

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**
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- e) **Determine the importance of genetic and environmental risk factors**
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**
Agree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**
Agree
- h) **Develop more representative animal and cell-based models of disease**
Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- a) Understand relationship between NDD and ageing

Second Priority

- d) Develop an improved understanding of the genetic basis

Third Priority

- b) Improve understanding of disease stages

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

- c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Yes. Some patients, especially those who have a faster progression of the disease or at end stage might be quite happy to participate.

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**

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**

Agree

d) **Develop a register of persons with cognitive impairment**

Strongly Agree

e) **Develop centres of excellence**

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) **Improve access to, and sharing of, infrastructure and resources**

Second Priority

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 foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) **Need for evidence-based policy**

Agree

b) **Ensure greater engagement with regulators**

Agree

c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Agree

d) **Encourage industry to adopt a pre-competitive approach to research**

Agree

e) **Rethink patent lifetime and conduct public-private clinical trials**

Agree

f) **Review and update legislation on treatment**

Strongly Agree

g) **Review and update legislation on privacy and data disclosure**

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) **Facilitate research in areas outside university and hospital sectors**

Second Priority

e) **Rethink patent lifetime and conduct public-private clinical trials**

Third Priority

f) **Review and update legislation on treatment**

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) **Translational research needs to be promoted**

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Strongly Agree

e) Maintain capacity for 'bottom-up' innovative funding

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Encourage open-access sharing of data and materials

Second Priority

a) Translational research needs to be promoted

Third Priority

e) Maintain capacity for 'bottom-up' innovative funding

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1863

Category of respondee

Person with Parkinson's

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

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

Neutral

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

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?

Research into the benefits of exercise and precisely what kind of exercise best promotes what, i.e. preservation of function and/or arresting the progress of the disease

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Agree

e) Rethink approaches to care

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

Neutral

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

Question 3: How would you define "care"?

Day to day promotion of the optimum physical and mental state of the patient by means of regularly reviewed care plans right from dx whether significantly impaired yet or not.

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

Strongly Agree

c) Conduct multi-centre primary prevention studies

Neutral

d) Ensure better patient selection/stratification

Neutral

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Strongly Agree

b) Improve understanding of disease stages

Neutral

c) Improve understanding of disease mechanisms

Strongly Agree

d) Develop an improved understanding of the genetic basis for NDD

Neutral

e) Determine the importance of genetic and environmental risk factors

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

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?

b) Neuronal inflammation

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

I do not know

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

Neutral

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

Neutral

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

e) Develop centres of excellence

Second Priority

d) Develop a register of persons with cognitive impairment

Third Priority

b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Is there no way in which parallel records whereby a patient is identified by name and where a duplicate anonymised record/ life history is automatically maintained and made available to researchers. At the moment the much talked about free access of patients records across the board in the NHS is (I was told today by the paramedics who attended my friend) inhibited by different Trusts all having their own interpretation of "data protection";, e.g.this may have been why we had to repeat my friends situation three times to different personnel whereas surely it should have appeared on the computer screen in front of each member of staff we spoke to.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

The only risk might be that they could be seen as a substitute for specialist nurses in the community as so often what is given on the one hand is taken away with the other.

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

Neutral

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

g) Review and update legislation on privacy and data disclosure

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**
Neutral
- d) **Simplify funding application systems**
Neutral
- e) **Maintain capacity for 'bottom-up' innovative funding**

Question 2: Please rank the suggestions in order of priority

First Priority

- e) Maintain capacity for 'bottom-up' innovative funding

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

1866

Category of respondee

Person with Parkinson's

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

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Strongly Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

c) Increase overall numbers of researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Disagree

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Strongly Agree

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

g) Conduct research into effects of nutrition and frailty

Second Priority

f) Understand and investigate influence of comorbidities on NDD

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Assistance with basic needs and friendship when needed

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Neutral

d) Ensure better patient selection/stratification

Neutral

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

f) Support for high-risk projects

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?

Publicise widely - TV perhaps - how important it is

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

b) Improve understanding of disease stages

c) Improve understanding of disease mechanisms

d) Develop an improved understanding of the genetic basis for NDD

e) Determine the importance of genetic and environmental risk factors

f) Focus research on rare hereditary forms of disease

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

h) Develop more representative animal and cell-based models of disease

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) Need for evidence-based policy**
- b) Ensure greater engagement with regulators**
- c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
- d) Encourage industry to adopt a pre-competitive approach to research**
- e) Rethink patent lifetime and conduct public-private clinical trials**
- f) Review and update legislation on treatment**
- g) Review and update legislation on privacy and data disclosure**

Question 2: Please rank the suggestions in order of priority

- First Priority**
- Second Priority**
- Third Priority**

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted**
- b) Encourage open-access sharing of data and materials**
- c) Joint academic-industry funding models**
- d) Simplify funding application systems**
- e) Maintain capacity for 'bottom-up' innovative funding**

Question 2: Please rank the suggestions in order of priority

- First Priority**
- Second Priority**
- Third Priority**

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1871

Category of respondee

Person with Parkinson's

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?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

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

c) Conduct multi-centre primary prevention studies

Second Priority

f) Support for high-risk projects

Third Priority

b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

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

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Agree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

Strongly Agree

h) Develop more representative animal and cell-based models of disease

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

e) Determine the importance of genetic and environmental risk factors

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?

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

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) Need for evidence-based policy**
- b) Ensure greater engagement with regulators**
- c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
- d) Encourage industry to adopt a pre-competitive approach to research**
- e) Rethink patent lifetime and conduct public-private clinical trials**
- f) Review and update legislation on treatment**
- g) Review and update legislation on privacy and data disclosure**

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted**
- b) Encourage open-access sharing of data and materials**
- c) Joint academic-industry funding models**
- d) Simplify funding application systems**
- e) Maintain capacity for 'bottom-up' innovative funding**

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1873

Category of respondee

Person with Parkinson's

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

Neutral

c) Increase numbers of neurodegenerative disease (NDD) researchers

Neutral

d) Increase training for translational and clinician-scientists

Neutral

e) Increase numbers of post-doctoral level researchers

Neutral

Question 2: If you had to choose one priority from the points above what would it be?

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Difficult for me to give too strong an opinion on this one as the treatment I receive at the University College London is first class!! What I don't know though is what if any treatment is available to me in the longer term.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Care standards in the NHS are always high, if they fall behind required standards don't we already have measures in place to correct this? Should we be spending money, time and effort on 'care' assessments across Europe? In my opinion, probably not.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Not Parkinson's specific other than helping younger sufferers come to terms with the condition that's regarded as an older person's disease. I didn't receive any assistance when I was first diagnosed at 32, I had two young children, a job and not a clue what to do next.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Promote independence as the main benefit of home care.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Neutral

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Disagree

e) Rethink approach to therapeutics

Strongly Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

Ask them

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

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

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

Agree

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority
Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) Need for evidence-based policy**
- b) Ensure greater engagement with regulators**
- c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**
- d) Encourage industry to adopt a pre-competitive approach to research**
- e) Rethink patent lifetime and conduct public-private clinical trials**
- f) Review and update legislation on treatment**
- g) Review and update legislation on privacy and data disclosure**

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

- a) Translational research needs to be promoted**
- b) Encourage open-access sharing of data and materials**
- c) Joint academic-industry funding models**
- d) Simplify funding application systems**
- e) Maintain capacity for 'bottom-up' innovative funding**

Question 2: Please rank the suggestions in order of priority

First Priority
Second Priority
Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

UID

1909

Category of respondee

Person with Parkinson's

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

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?

to develop holistic approaches across medical fields to look at the whole person not just pieces

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Strongly Agree

b) Survey long-term care standards and provision across Europe

Strongly Agree

c) Research into the needs of carers

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

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

b) Survey long-term care standards and provision across Europe

Second Priority

a) Define the term "care"

Third Priority

d) Research end of life decision making

Question 3: How would you define "care"?

to allow/ facilitate a person to live their life without disadvantage
a partnership between health, patients and support teams
a helpful relationship on equal terms

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

holistic multi disciplinary approaches to ensure well being and empowerment

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

Strongly Agree

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Disagree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

a) Increase involvement of individuals in research

Third Priority

c) Conduct multi-centre primary prevention studies

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

to feedback outcomes and the importance of steps more easily accessible material less jargon when writing make information feedback SMART think about how you publise info

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

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

a) Understand relationship between NDD and ageing

Third Priority

c) Improve understanding of disease mechanisms

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

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

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Neutral

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Agree

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

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

b) Improve access to patient groups, samples and data

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Strongly Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

d) Encourage industry to adopt pre-competitive approach

Second Priority

a) Need for evidence-based policy

Third Priority

b) Ensure greater engagement with regulators

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Strongly Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Agree

e) Maintain capacity for 'bottom-up' innovative funding

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Translational research needs to be promoted

Second Priority

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

1911

Category of respondee

Person with Parkinson's

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

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

b) Improve education and training of healthcare professionals

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Strongly Agree

b) Survey long-term care standards and provision across Europe

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

Strongly 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

f) Understand and investigate influence of comorbidities on NDD

Third Priority

g) Conduct research into effects of nutrition and frailty

Question 3: How would you define "care"?

Having the interest of the patient at heart. Knowing what help is desired, needed and acceptable. The ability to give the help that is required. Being aware of the importance of quality of life.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Talking to carers and patients together to ascertain that they understand each others needs regarding quality of life.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

The greater the support given to carers and patients at the outset, the greater hope of overcoming initial disadvantages and understanding the mutual advantages.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Strongly Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Strongly Agree

e) Rethink approach to therapeutics

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

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?

By making it more easily accessible and increasing understanding of what is involved.

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

b) Improve understanding of disease stages

c) Improve understanding of disease mechanisms

d) Develop an improved understanding of the genetic basis for NDD

e) Determine the importance of genetic and environmental risk factors

f) Focus research on rare hereditary forms of disease

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

h) Develop more representative animal and cell-based models of disease

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

b) Redefine and harmonise clinical endpoints and outcomes

c) Develop new biomarkers

d) Consider regulatory approaches

Question 2: Which of the following do you think is most important in terms of biomarkers?

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

b) Improve access to patient groups, samples and data

c) Improve data and sample collection

d) Develop a register of persons with cognitive impairment

e) Develop centres of excellence

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

d) Simplify funding application systems

e) Maintain capacity for 'bottom-up' innovative funding

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal

Concluding questions

Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)

Question 2: Do you have any comments on how to implement the above suggestion(s)?

Question 3: Is there anything else you would like to tell us?

From the point of view of being a person with Parkinson's I thank you for the opportunity to take part and believe it is an excellent initiative that will provide invaluable input from all sectors. Thank You

UID

1913

Category of respondee

Carer for person with Parkinson's

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

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

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

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

Neutral

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

c) Research into the needs of carers

Question 3: How would you define "care"?

Looking after someone's physical and mental/emotional health needs and enabling participation in society.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Need to only take individual resources into account when allocating funding, not the partners as well.

Otherwise funds may be exhausted and then the other partner is left without any way to fund their own future care.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

More support for families with carrying out caring responsibilities.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Neutral

d) Ensure better patient selection/stratification

Neutral

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Promote development of non-pharmacological interventions

Second Priority

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?

Make brain donation registration possible online. Make more use of the internet to let people know about research trials and enable them to register their interest.

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

Strongly Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Disagree

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

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

d) Develop an improved understanding of the genetic basis

Third Priority

g) Establish pan-European population-based studies

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

c) Mechanisms of neuronal death and dysfunction

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Neutral

c) Improve data and sample collection

Neutral

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

Agree

f) Review and update legislation on treatment

Neutral

g) Review and update legislation on privacy and data disclosure

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) Translational research needs to be promoted

Agree

b) Encourage open-access sharing of data and materials

Agree

c) Joint academic-industry funding models

Agree

d) Simplify funding application systems

Neutral

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

1920

Category of respondee

Person with Parkinson's

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?

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

e)

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

Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Strongly Agree

f) Understand and investigate influence of comorbidities

Neutral

g) Conduct research into effects of nutrition and frailty

Agree

h) Determine cost-effectiveness of healthcare pathways

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Survey long-term care standards and provision across Europe

Second Priority

e) Rethink approaches to care

Third Priority

d) Research end of life decision making

Question 3: How would you define "care"?

A framework of comprehensive provision which is focused on the individual needs of patients and takes into account their views on HOW their medical and social needs are met and, whilst needing to be cost-effective, is not constrained by interorganisationa

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

End the division between health and social care.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

It needs to be less confusing and have a single point of onctact to address needs.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Strongly Agree

b) Promote development of non-pharmacological interventions

Agree

c) Conduct multi-centre primary prevention studies

Strongly Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

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?

More public information e.g. similar to organ 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?

Don't know.

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

Agree

h) Develop more representative animal and cell-based models of disease

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

c) Improve understanding of disease mechanisms

Second Priority

a) Understand relationship between NDD and ageing

Third Priority

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?

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

Agree

- d) Develop a register of persons with cognitive impairment
- 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

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

- a) Need for evidence-based policy

Agree

- b) Ensure greater engagement with regulators

Strongly Agree

- 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

1921

Category of respondee

Person with Parkinson's

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?

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

Strongly Agree

d) Research into care approaches including end of life decision-making

Strongly Agree

e) Rethink approaches to care

Neutral

f) Understand and investigate influence of comorbidities

Strongly Agree

g) Conduct research into effects of nutrition and frailty

Strongly 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

c) Research into the needs of carers

Third Priority

b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?

Caring is a difficult concept to define, perhaps defining what I would expect from someone who cares for me is slightly easier! A carer should be someone who is empathetic; kind; considerate; (again difficult concepts to define) patient; a good listener;

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Listen to the person with the disease - they are the experts! Allowing people to retain control over their care is essential. These things are easily adopted by including patients and carers in the research team and undertaking more qualitative research with these groups to find out what their care needs/priorities are and their experiences of living with this condition. These studies whilst not generalisable, can provide vital information for researchers to plan future large scale studies. Any revision of care services must be evidence based and not based on financial /political constraints.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Although I have ticked the patient box at the beginning of this survey I am currently still in work and do not require any care either at home or in a care facility. I am therefore answering this question based on my knowledge of the research relating to caring for anyone with a debilitating disease in their own homes. It seems that the provision of regular support is the biggest issue, having someone for carers to talk to and get advice from as and when needed is important. Most people would prefer to remain in their own homes being cared for by their families (which of course is the cheapest option for health boards). But regular support and respite must be offered, as research has shown that the burden of caring can have an enormous impact on the carers health and well-being.

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**
Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

- c) Conduct multi-centre primary prevention studies

Second Priority

- a) Increase involvement of individuals in research

Third Priority

- b) Promote development of non-pharmacological interventions

Question 3: How can we encourage more people to take part in research and/or register to donate brain material?

People are more likely to take part in research if they are well informed about the nature of the research and how it may help them or more likely other people with the disease in the future. Its difficult to get this information to all potential participants, though using brightly coloured information sheets which stand out from the rest of the usual mail sometimes works. The use of posters in community centres, GP surgeries, hospital departments, even the local newspaper can also be effective. If people think that there is nothing in it for them they are less likely to volunteer and I am not keen on the idea of offering incentives. Recruiting via clinic or GP practice staff is probably the most effective way of recruiting as people who have a face to face explanation of the nature and purpose of the research rather than having a leaflet through the door are more likely to agree to participate.

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?

Sorry- I am not sure what you are asking here - outcome measures???

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

- a) **Understand relationship between neurodegenerative disease and ageing**
Agree
- b) **Improve understanding of disease stages**
Strongly Agree
- c) **Improve understanding of disease mechanisms**
Agree
- d) **Develop an improved understanding of the genetic basis for NDD**
Agree
- 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**
Neutral

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

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

I do not feel sufficiently qualified to answer this sorry.

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?

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

Strongly Agree

b) Improve access to patient groups, samples and data

Strongly Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

b) Improve access to patient groups, samples and data

Second Priority

a) Improve access to, and sharing of, infrastructure and resources

Third Priority

c) Improve data and sample collection

Question 3: What can be done to facilitate increased sharing of data?

Researchers need to collaborate more with each other, this happens now in many areas though there is always room to develop this further. Research grants /funding should only be given to multi-centre research to ensure that there is cross collaboration bet

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

As long as the data is anonymised then I would have no problem in there being open access. Participants may need to consent to this though at the start of the study.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

I think this is the only way to ensure that good quality research is conducted. If there are lots of researchers carrying out pockets of research in a range of areas then the data may lack the rigour needed to produce reliable and valid data which then does not lend itself to the development of knowledge about the disease etc... By establishing centres of excellence programmes of research focused on specific areas of the disease process/quality of life issues, can be planned and managed in collaboration with smaller institutions /and other centres of excellence. This should result in better quality and focused research which can be used to inform care.

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Strongly Agree

d) Encourage industry to adopt a pre-competitive approach to research

Neutral

e) Rethink patent lifetime and conduct public-private clinical trials

Neutral

f) Review and update legislation on treatment

Agree

g) Review and update legislation on privacy and data disclosure

Strongly Agree

Question 2: Please rank the suggestions in order of priority

First Priority

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

e) Maintain capacity for 'bottom-up' innovative funding

Second Priority

b) Encourage open-access sharing of data and materials

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

1996

Category of respondee

Person with Parkinson's

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

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?

Patients, on first diagnosis, should have better access to information about the disease and its likely or possible progression, what facilities are available such as support groups, what drugs are used and why and when, etc. When my PD was diagnosed I knew little about the disease. I went and did my own research on the internet and in the library and by talking to people. Other people might not be able to do this.

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

e) Rethink approaches to care

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"?

Care has two quite separate meanings. 1. Being concerned about another human being or animal, or even an abstraction. This leads to the idea of looking after someone, which had led to the second meaning 2. Providing the everyday requirements of life, including those activities done by the person concerned before he or she became unable to do them. Does not necessarily imply on the part of the carer, but ideally it should.

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?

More electronic monitoring and communication might help to avoid the situation where a disabled person is on his/her own for long periods and has to wait till the carer arrives.

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

- a) **Increase involvement of individuals in research**
Strongly Agree
- b) **Promote development of non-pharmacological interventions**
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**
Agree
- d) **Ensure better patient selection/stratification**
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

- 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?

More publicity directed to the people concerned when they are younger and more able to think things through.

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 do not really understand what you mean by this concept.

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**
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

Second Priority

Third Priority

Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

- a) **Redefine and standardise disease definitions and diagnosis**

Agree

b) Redefine and harmonise clinical endpoints and outcomes

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

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) Need for evidence-based policy

Agree

b) Ensure greater engagement with regulators

Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

Agree

d) Encourage industry to adopt a pre-competitive approach to research

Agree

e) Rethink patent lifetime and conduct public-private clinical trials

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

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

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

1998

Category of respondee

Person with Parkinson's

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

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Agree

Question 2: If you had to choose one priority from the points above what would it be?

a) Improve dialogue between researchers and wider population

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

b) Survey long-term care standards and provision across Europe

c) Research into the needs of carers

d) Research into care approaches including end of life decision-making

e) Rethink approaches to care

f) Understand and investigate influence of comorbidities

g) Conduct research into effects of nutrition and frailty

h) Determine cost-effectiveness of healthcare pathways

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

Neutral

c) Conduct multi-centre primary prevention studies

Agree

d) Ensure better patient selection/stratification

Agree

e) Rethink approach to therapeutics

Agree

f) Support for high-risk projects

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

a) Increase involvement of individuals in research

Second Priority

c) Conduct multi-centre primary prevention studies

Third Priority

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?

make sure that patients hear about research for their conditions

Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?

Disease cause, mechanisms and models

Question 1: Please indicate to what extent you endorse the following points

a) Understand relationship between neurodegenerative disease and ageing

Agree

b) Improve understanding of disease stages

Agree

c) Improve understanding of disease mechanisms

Agree

d) Develop an improved understanding of the genetic basis for NDD

Agree

e) Determine the importance of genetic and environmental risk factors

Agree

f) Focus research on rare hereditary forms of disease

Neutral

g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups

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?

d) The biological basis of behavioural and psychological symptoms

Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable

More acceptable to volunteers who are very ill and near the end

Diagnosis, disease definitions and outcome measures

Question 1: Please indicate to what extent you endorse the following points

a) Redefine and standardise disease definitions and diagnosis

Agree

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Neutral

d) Consider regulatory approaches

Neutral

Question 2: Which of the following do you think is most important in terms of biomarkers?

b) Linking to treatment responses

Data, registries, repositories and centres

Question 1: Please indicate to what extent you endorse the following points

a) Improve access to, and sharing of, infrastructure and resources

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**

Agree

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: What can be done to facilitate increased sharing of data?

Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?

Policy, regulation and legislation

Question 1: Please indicate to what extent you endorse the following points

a) **Need for evidence-based policy**

Agree

b) **Ensure greater engagement with regulators**

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**

Strongly Agree

e) **Rethink patent lifetime and conduct public-private clinical trials**

Agree

f) **Review and update legislation on treatment**

Neutral

g) **Review and update legislation on privacy and data disclosure**

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

Second Priority

Third Priority

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points

a) **Translational research needs to be promoted**

Agree

b) **Encourage open-access sharing of data and materials**

Strongly Agree

c) **Joint academic-industry funding models**

Strongly 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

b) Encourage open-access sharing of data and materials

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?