Directory of general public & other respondees

Responses from individuals

ID code	Title	First Name	Last Name	Country	Page
1721	Mrs	Raquel	Caba	Spain	2
1827	Miss	Lucie	Clough	United Kingdom	7
2071	Dr	Alvy	Derks	Netherlands	12

Anonymous responses from individuals

ID code	Country	Page
1874	United Kingdom	17

UID
   1721
Title
   Mrs
First Name
   Raquel
Surname
   Caba
Category of respondee
   General public or other
Country
   Spain

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?
   d) Increase training for translational and clinician-scientists

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

Health and social care issues

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

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

c) Research into the needs of carers
   Strongly Agree

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

e) Rethink approaches to care
   Strongly Agree

f) Understand and investigate influence of comorbidities
   Neutral

g) Conduct research into effects of nutrition and frailty
   Neutral

h) Determine cost-effectiveness of healthcare pathways
   Strongly Agree

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

    h) Determine cost-effectiveness of healthcare pathways

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

Third Priority
    c) Research into the needs of carers

Question 3: How would you define "care"?

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

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

Prevention/treatment strategies and trials

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

b) Promote development of non-pharmacological interventions
    Strongly Agree

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
    b) Promote development of non-pharmacological interventions

Second Priority
    e) Rethink approach to therapeutics

Third Priority
    f) Support for high-risk projects

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

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

Disease cause, mechanisms and models

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

b) Improve understanding of disease stages
    Strongly Agree

c) Improve understanding of disease mechanisms
    Agree

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

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

f) Focus research on rare hereditary forms of disease
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
Neutral

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
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
Strongly Agree

b) Redefine and harmonise clinical endpoints and outcomes
Agree

c) Develop new biomarkers
Agree

d) Consider regulatory approaches

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

Data, registries, repositories and centres

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

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

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

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

Third Priority
   c) Improve data and sample collection

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

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

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

Policy, regulation and legislation

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

b) Ensure greater engagement with regulators
   Agree

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

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

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

f) Review and update legislation on treatment
   Disagree

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

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

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

Third Priority
   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
c) Joint academic-industry funding models
   Strongly 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
    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)
    Provide opportunities for small an research businesses

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
1827
Title
Miss
First Name
Lucie
Surname
Clough
Category of respondee
General public or other
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
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?
I think more needs to be done about raising awareness of the symptoms of neuro degenerative diseases particularly Parkinson's disease.   More support to be provided for people with parkinson's, there is currently not enough support for people who are diagnoses and this is when they need support, advice and reassurance. My Father was informed and there was no offer of support or counselling.

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term "care"
Agree

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

c) Research into the needs of carers
Strongly Agree

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

e) Rethink approaches to care
Agree

f) Understand and investigate influence of comorbidities
Neutral

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
d) Research end of life decision making

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

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

Question 3: How would you define "care"?
I would define care as looking after someone emotionally, mentally and physically taking their wishes into account. I think care can also mean providing support, understanding and empathy, along with medical care...which is about treating the person in a holistic way. I think this country tends to treat conditions in isolation without always thinking about how symptoms are interlinked or indicative of something more serious. Illness seems to be treated in the immediate without forward thinking.

Question 4: Have you any (additional) suggestions as to how care systems should be revised?
I more support should be provided for people diagnosised with long term conditions, particularly for those people who may not have family and friends to support them.

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 do not think it should be about cost saving to the NHS, it should be about patient choice and what suits their needs best. There is no point discharging someone early for them to be admitted a few days later etc...which must incur more of a cost to the NHS.

Prevention/treatment strategies and trials

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

b) Promote development of non-pharmacological interventions
Strongly Agree

c) Conduct multi-centre primary prevention studies
Agree

d) Ensure better patient selection/stratification
Neutral

e) Rethink approach to therapeutics
Strongly Agree

f) Support for high-risk projects
Neutral

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

Second Priority
b) Promote development of non-pharmacological interventions

Third Priority
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?

I'm not sure, the benefits would need to be clearly explained. This is also very complex and upsetting for people to think about at any stage, including the family. I don't know how I feel about this really, would need to learn more about it.

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?

Not sure what this means sorry. I would like more research done into the harm that pesticides etc do on food that is consumed (when unwashed) I would also like to know the effect of Anti depressants on causing NDD as both my Gran and Father have been on them for years and both ended up having an NDD. Please would someone do further research into this?

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

Neutral

e) Determine the importance of genetic and environmental risk factors

f) Focus research on rare hereditary forms of disease

Strongly Agree

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

Neutral

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

Agree

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

b) Improve understanding of disease stages

Second Priority

f) Focus research on rare hereditary forms of disease

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?

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

b) Redefine and harmonise clinical endpoints and outcomes

Strongly Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches
Neutral

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

Data, registries, repositories and centres

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

b) Improve access to patient groups, samples and data
Strongly Agree
c) Improve data and sample collection
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
a) Improve access to, and sharing of, infrastructure and resources

Third Priority
e) Develop centres of excellence

Question 3: What can be done to facilitate increased sharing of data?
Creating networks like we have for Cancer Networks. I think a national awareness campaign needs to take place in the UK, this is well overdue.   Data sharing can be done by having clinical champions across the UK, similar to what we have done for HeadSmart - be brain tumour aware.

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

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
Yes, this means there could be a postcode lottery. How would you determine which patients attend the centre of excellence and how would patients feel if they wanted to attend and could not.....saying that there are CCLGs - Cancer Centres of Excellence seem to do this well. Perhaps take some learning from them?

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
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
c) Facilitate research in areas outside university and hospital sectors

Third Priority
b) Ensure greater engagement with regulators

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?
Thorough history taking of patients in terms of eating habits, supplements taken, medicines taken e.g SSRIs, chemicals they were frequently exposed to. We need to find the causes before we can find a cure.

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
Agree

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

d) Simplify funding application systems
Agree

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

Question 2: Please rank the suggestions in order of priority
First Priority
b) Encourage open-access sharing of data and materials

Second Priority
a) Translational research needs to be promoted

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
People should sign to terms and conditions of data sharing . Possibly have an opt out rather than opt in system in organisations?

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?
Thank you for doing this research, I would be keen to know the results and what you plan to do next.   BW   Lucie Clough

UID
 2071
Title
 Dr
First Name
 Alvy
Surname
 Derks
Category of respondee
 General public or other
Country
 Netherlands

Education, training and collaboration

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

b) Improve education and training of healthcare professionals
 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?
 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?
 Dissemination of knowledge about genetic based diseases

Health and social care issues

Question 1: Please indicate to what extent you endorse the following points
a) Define the term "care"
 Agree

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

c) Research into the needs of carers
 Strongly Agree

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

e) Rethink approaches to care
 Agree

f) Understand and investigate influence of comorbidities
 Strongly 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
   b) Survey long-term care standards and provision across Europe

Question 3: How would you define "care"?
   Strive to maintain or improve (the conditions of) good health and well-being

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?
   Support and possibility of leave 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
   Neutral

b) Promote development of non-pharmacological interventions
   Strongly Agree

c) Conduct multi-centre primary prevention studies
   Strongly Agree

d) Ensure better patient selection/stratification
   Strongly Agree

e) Rethink approach to therapeutics
   Agree

f) Support for high-risk projects
   Agree

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

Second Priority
   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?
   Via unions and associations of older people

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
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
d) Develop an improved understanding of the genetic basis

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?
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
I doubt.

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
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
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
Agree

e) Develop centres of excellence
  Agree

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

Second Priority
  c) Improve data and sample collection

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

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

Question 4: What are your views on making data open access? If you forsee difficulties, how can we overcome these?
  No problems if privacy is quaranteed

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
  Agree

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

f) Review and update legislation on treatment
  Agree

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

Question 2: Please rank the suggestions in order of priority
First Priority
  c) Facilitate research in areas outside university and hospital sectors

Second Priority
  a) Need for evidence-based policy

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

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

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
  Strongly Agree

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

d) Simplify funding application systems
Agree

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

Question 2: Please rank the suggestions in order of priority
First Priority
b) Encourage open-access sharing of data and materials

Second Priority
a) Translational research needs to be promoted

Third Priority
c) Joint academic-industry funding models

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

Concluding questions

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

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

Question 3: Is there anything else you would like to tell us?
Differentiation between data of men and women

User ID
1874
Category of respondee
  General Public
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?
  I do not feel that doctors have sufficient awareness of the mental effects of Parkinson's and do not do enough to monitor this.

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
  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
  e) Rethink approaches to care

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"?
  The provision of what is necessary for someone's health, welfare, protection and maintenance of a normal life.

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

AS soon as someone is diagnosed with Parkinson's they should be encouraged to involve a friend or family member with their care and they should be educated on Parkinson's. What the disease can do, particularly its mental effects, as this would mean that you were looking out for these signs and could seek help for the patient before things progress to far. This is of particular importance for single people as they appear to be sent home and left to their own devices until they need more tablets, when they are given a very brief chat with a GP- who doesn't understand the condition, before they are packed off with more of the same tablets.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?
Provision of care at home relies very heavily on the carer, who is given very little support. Carers should be involved at an earlier stage; they should be given emotional support and advice, assistance to obtain benefits and easier access to healthcare professionals. Care at home can mean that the condition slips as the patient may be in denial about the progression of the condition or be unaware of mental changes. This can mean that they ignore or fight against their carers concerns. A lack of regular and consistent contact and support from any healthcare professional can damage the patient carer relationship. I have seen the carer being bullied into not pursuing help and the patient acting their way through the short 10 minute doctor's appointment and appearing fine to the GP who doesn't know them.   Seeing different doctors for a few minutes is next to useless in monitoring the progression of this condition and does not allow a patient to build a good relationship where they feel safe to admit to mental health or embarrassing physical changes.

Prevention/treatment strategies and trials

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

b) Promote development of non-pharmacological interventions
Agree

c) Conduct multi-centre primary prevention studies
Agree

d) Ensure better patient selection/stratification
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
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?
I have seen a number of trials which are based only in one small part of the country, look at ways to roll out trials to a more widespread geographical area. You need to make the research trials more accessible, using the network of supporters and carers, social workers and GPs to help run trials. Even something a simple as data collection can easily be done by the above and can also be assessed by non medical staff/volunteers. Through increasing involvement in trials, awareness increases and more people may be willing to donate brain material.   In particular people who have suffered mental health issues as a result of Parkinson's for example, may be willing to donate. If you have had some involvement in research and have connected with it personally, rather than a distant trial of unknown people miles away, you relate to it and may be much more willing to donate.

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
>   Neutral

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

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

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

a) Linking to the mechanism of disease and functional endpoints

Data, registries, repositories and centres

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

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

c) Improve data and sample collection
Strongly Agree

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

e) Develop centres of excellence
Strongly Agree

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

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

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

Question 3: What can be done to facilitate increased sharing of data?
Encourage existing patients and families to push for this so that all existing data can be more effectively used and for patients to be asked to only agree to participate if data is shared.

Question 4: What are your views on making data open access? If you forsee difficulties, how can we overcome these?
data should be open access if it has no personal info what is the harm from a patients point of view.

Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?
They may become too focussed on their own geographical area and resources diverted to a few areas instead of around the country. Also if there are only a few centres, patient care may suffer, as anyone close enough to benefit from a centre of excellence may get better care. Every local hospital should have a specialist unit for patient care, centres of excellence for research purposes are not as critical to be spread around the country but in terms of patient treatment they are. Setting up a centre of excellence should not be an excuse to close other more local valuable resources, as too often appears to be the case.

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
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
    d) Encourage industry to adopt pre-competitive approach

Second Priority
    f) Review and update legislation on treatment

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

Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?
    Research into the cost and quality of residential care of people with such diseases on a long term basis. Better treatment and long term care could enable people to remain in their own home or with family for longer and also to highlight the quality of care may encourage people to support improvements in research.

Funding and funding mechanisms

Question 1: Please indicate to what extent you endorse the following points
a) Translational research needs to be promoted
    Neutral

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

c) Joint academic-industry funding models
    Neutral

d) Simplify funding application systems
    Neutral

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

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 feel that involving a person in monitoring their own condition and having a facility to report their data back could assist in research.   For example a patient can register from diagnosis stage, to an online information and support website. They could access information to assist with their condition and can complete an online tracker. The trackers could be accessed and monitored by researchers, you could also build in trigger questions, where if a patient answers a question in a

certain way it would flag up with a researcher or health professional to contact the patient.   Also, as some research wants people with a condition at a certain stage- the trigger question could flag up potential participants at the correct stage of their condition.

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

This would be very simple to implement as the patient and or carer would register themselves. All information would be instantly accessible to researchers.

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

I feel that the level of care given by Gps, consultants and social workers is very disjointed and insufficient time is allocated to patients by consultants to accurately assess their condition.   I have seen a patient deteriorate to having visions, setting his house on fire- to cleanse it of spirits, being sectioned then released. Later giving a car away for a penny- whilst his social worker was in the room!!!! and being targeted by thugs who took thousands of pounds off him whilst he was mentally altered by Parkinson's medication. All this whilst being able to hold a fairly normal conversation for a few minutes- so his GP would ask him how he was- he said fine - so off he went with more drugs. This condition cannot be treated like others, people do not understand the mental impact of Parkinson's, even GPs need to understand its more than a shaky hand!