

## Directory of healthcare professional respondees

<b>Responses from organisations/institutions</b>						
<b>ID code</b>	<b>Organisation/institutions</b>			<b>Country</b>	<b>Page</b>	
1539	Liaisonpsychiatric Unit, Copenhagen University Hospital Bispebjerg			Denmark	3	
1628	Association Luxembourgeoise de Gérontologie			Luxembourg	7	
1744	West Hertfordshire NHS Hospitals NHS Trust			United Kingdom	11	
1792	AGILE: Chartered Physiotherapists working with Older People			United Kingdom	15	
1795	Swedish Assosiation of Geriatric Medicine			Sweden	19	
1894	Sociedad Española de Geriatria y Gerontología			Spain	23	
1907	University Hospital of Strasbourg			France	27	
1930	St James's Hospital/Trinity College Dublin			Ireland	31	
1995	Azienda Unita' Sanitaria Locale Di Modena			Italy	35	
2018	Zorggroep Noorderbreedte, Leeuwarden			Netherlands	39	
2080	Opsedale S.Anna Ferrara			Italy	43	
<b>Anonymous responses from organisations/institutions</b>						
<b>ID code</b>	<b>Country</b>				<b>Page</b>	
2060	United Kingdom				47	
<b>Responses from individuals</b>						
<b>ID code</b>	<b>Title</b>	<b>First Name</b>	<b>Last Name</b>	<b>Profession</b>	<b>Country</b>	<b>Page</b>
1580	Professor	Desmond	O'Neill	Geriatrician	Ireland	51
1586	Dr	Tayyeb	Tahir	Liaison Psychiatrist	United Kingdom	55
1621	Professor	Koen	Van Laere	Nuclear Medicine	Belgium	59
1651	Dr	Georgios	Spatharakis	Primary Health Care	Greece	63
1768	Dr	Michael	Watts	Geriatrician	Ireland	67
1893	Dr	Morillas	Manuel	Hospital Administrator	Spain	71
1971	Professor	Rowan	Harwood	Geriatrician	United Kingdom	75
2006	Dr	Elizabeth	Coulthard	Neurology Consultant	United Kingdom	79
2034	Dr	Nenad	Bogdanovic	Geriatrician	United Kingdom	83
2135	Dr	Ales	Kogoj	Psychiatrist	Slovenia	87
2157	Professor	Timothy	Lynch	Consultant Neurologist	Ireland	91
2046	Dr	Charlotte	Morgan	General Practitioner	United Kingdom	95

<b>Anonymous responses from individuals</b>		
<b>ID code</b>	<b>Country</b>	<b>Page</b>
1515	Norway	99
1666	United Kingdom	103
1715	United Kingdom	107
1963	Slovenia	111
2145	Italy	115

An additional 5 responses were received from individuals who requested that their submission be used for no other purpose than in the overall analysis of responses.

**UID**

1539

**Title**

Senior Consultant

**First Name**

Jens

**Surname**

Norbaek

**Category of respondee**

Healthcare professional – Psychiatrist

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

Liaisonpsychiatric Unit, Copenhagen University Hospital Bispebjerg

**Country**

Denmark

## Education, training and collaboration

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

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

Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

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

Agree

**d) Increase training for translational and clinician-scientists**

Agree

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

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

b) Improve education and training of healthcare professionals

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

## Health and social care issues

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

**a) Define the term "care"**

Neutral

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

Neutral

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

Agree

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

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

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

Agree

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

Agree

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

**First Priority**

h) Determine cost-effectiveness of healthcare pathways

**Second Priority**

f) Understand and investigate influence of comorbidities on NDD

**Third Priority**

c) Research into the needs of carers

**Question 3: How would you define "care"?**

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

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

## Prevention/treatment strategies and trials

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

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

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

**First Priority**

- e) Rethink approach to therapeutics

**Second Priority**

- c) Conduct multi-centre primary prevention studies

**Third Priority**

- b) Promote development of non-pharmacological interventions

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

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

## Disease cause, mechanisms and models

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

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

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

**First Priority**

- c) Improve understanding of disease mechanisms

**Second Priority**

- d) Develop an improved understanding of the genetic basis

**Third Priority**

- g) Establish pan-European population-based studies

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

- b) Neuronal inflammation

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

## Diagnosis, disease definitions and outcome measures

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

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

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

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

## Data, registries, repositories and centres

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

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

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

**First Priority**

- e) Develop centres of excellence

**Second Priority**

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

**Third Priority**

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

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

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

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

## Policy, regulation and legislation

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

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

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

**First Priority**

- a) Need for evidence-based policy

**Second Priority**

- b) Ensure greater engagement with regulators

**Third Priority**

- f) Review and update legislation on treatment

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

## Funding and funding mechanisms

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

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

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

**First Priority**

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

**Second Priority**

- a) Translational research needs to be promoted

**Third Priority**

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

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

## Concluding questions

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

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

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

**UID**

1628

**Title**

Dr

**First Name**

Jean-Claude

**Surname**

Leners

**Category of respondee**

Healthcare professional - Geriatrician

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

Association Luxembourgeoise de Gérontologie

**Country**

Luxembourg

## Education, training and collaboration

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

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

Strongly Agree

**b) Improve education and training of healthcare professionals**

Agree

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

Agree

**d) Increase training for translational and clinician-scientists**

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?**

palliative care and alzheimer 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**

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**

h) Determine cost-effectiveness of healthcare pathways

**Second Priority**

d) Research end of life decision making

**Third Priority**

e) Rethink approaches to care

**Question 3: How would you define "care"?**

assist as wished by the client in an highly ethical way

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

large long term care facilities are past, historical institutions of no added value for people with dementia

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

## Prevention/treatment strategies and trials

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

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

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

**First Priority**

- a) Increase involvement of individuals in research

**Second Priority**

- e) Rethink approach to therapeutics

**Third Priority**

- b) Promote development of non-pharmacological interventions

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

- promote living will in all countries

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

- multilingualism, creativity as prevention

## Disease cause, mechanisms and models

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

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

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

**First Priority**

- g) Establish pan-European population-based studies

**Second Priority**

- b) Improve understanding of disease stages

**Third Priority**

- c) Improve understanding of disease mechanisms

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

- d) The biological basis of behavioural and psychological symptoms

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

no idea

## Diagnosis, disease definitions and outcome measures

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

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

Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Agree

**c) Develop new biomarkers**

Neutral

**d) Consider regulatory approaches**

Neutral

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

b) Linking to treatment responses

## Data, registries, repositories and centres

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

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

Agree

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

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

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

Agree

**e) Develop centres of excellence**

Strongly Agree

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

**First Priority**

e) Develop centres of excellence

**Second Priority**

d) Develop a register of persons with cognitive impairment

**Third Priority**

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

work with data existing in our country but no researchers paid to work on them !!!

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

more a legal aspect which i cannot answer

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

no

## Policy, regulation and legislation

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

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

Agree

**b) Ensure greater engagement with regulators**

Agree

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

Strongly Agree

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

Neutral

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

Agree

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

Neutral

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

Neutral

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

**First Priority**

- a) Need for evidence-based policy

**Second Priority**

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

**Third Priority**

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

## Funding and funding mechanisms

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

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

Strongly Agree

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

Strongly Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

Agree

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

Agree

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

**First Priority**

- a) Translational research needs to be promoted

**Second Priority**

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

**Third Priority**

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

## Concluding questions

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

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

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

nearly no offer for research in this field in luxembourg!!!

**UID**

1744

**Title**

Dr

**First Name**

Valerie

**Surname**

Page

**Category of respondee**

Healthcare professional - Consultant in Critical Care

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

West Hertfordshire NHS hospitals NHS Trust

**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**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Neutral

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

d) Increase training for translational and clinician-scientists

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

Accessible statistics both in terms of actual access to statisticians and enabling clinicians to understand statistics, training for the ignorant interested.

## Health and social care issues

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

**a) Define the term "care"**

Disagree

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

Strongly Agree

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

Agree

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

Neutral

**e) Rethink approaches to care**

Neutral

**f) Understand and investigate influence of comorbidities**

Disagree

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

Agree

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

Agree

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

**First Priority**

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

**Second Priority**

g) Conduct research into effects of nutrition and frailty

**Third Priority**

**Question 3: How would you define "care"?**

An umbrella term to describe a designer approach to each individual in order to nurture a human being physically, intellectually and emotional - where nurturing means enabling a person to reach their potential at any given time or stage in their lives. Care will therefore need to include others.

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

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

More flexibility and initiative to be encourage in health care workers - less emphasis on tick boxes and time restraints where-ever possible.

## Prevention/treatment strategies and trials

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

**a) Increase involvement of individuals in research**

Agree

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

Neutral

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Disagree

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Disagree

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

**First Priority**

c) Conduct multi-centre primary prevention studies

**Second Priority**

**Third Priority**

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

Promote the current ways of working that are a result of individuals in the past taking part in research.

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

Prevention of delirium - mobilisation programme for the patients at risk, cognition programme.

## Disease cause, mechanisms and models

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

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

Disagree

**b) Improve understanding of disease stages**

Neutral

**c) Improve understanding of disease mechanisms**

Agree

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

Neutral

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

Agree

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

Neutral

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

Agree

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

Agree

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

**First Priority**

**Second Priority**

**Third Priority**

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

c) Mechanisms of neuronal death and dysfunction

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

## Diagnosis, disease definitions and outcome measures

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

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

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

- b) [Linking to treatment responses](#)

## Data, registries, repositories and centres

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

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

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

**First Priority**

- c) [Improve data and sample collection](#)

**Second Priority**

- a) [Improve access to, and sharing of, infrastructure and resources](#)

**Third Priority**

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

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

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

[Withdrawal of resources and expertise from institutions which likely have access to large heterogenous patient population for study opportunities. Competition within centre of excellence for individual patients to participate in the different trials.](#)

## Policy, regulation and legislation

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

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

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

**First Priority**

**Second Priority**

**Third Priority**

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

## Funding and funding mechanisms

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

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

- c) Joint academic-industry funding models
- d) Simplify funding application systems
- e) Maintain capacity for 'bottom-up' innovative funding

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

**First Priority**

**Second Priority**

**Third Priority**

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

## **Concluding questions**

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

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

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

**UID**

1792

**Title**

Mrs

**First Name**

Janet

**Surname**

Thomas

**Category of respondee**

Healthcare professional - Physiotherapist

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

AGILE: Chartered Physiotherapists working with Older People

**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"**

Neutral

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

Strongly Agree

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

Strongly Agree

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

Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Agree

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

Agree

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

Strongly Agree

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

**First Priority**

e) Rethink approaches to care

**Second Priority**

h) Determine cost-effectiveness of healthcare pathways

**Third Priority**

c) Research into the needs of carers

**Question 3: How would you define "care"?**

Care should encompass a range of requirements based on the needs of the individual concerned. Care can range from meeting all an individuals personal and social needs to enabling someone to meet those needs for themselves

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

Must be able to be personalized and individualized and reactive to quickly changing conditions

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

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

## Prevention/treatment strategies and trials

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

**a) Increase involvement of individuals in research**

Neutral

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

Agree

**c) Conduct multi-centre primary prevention studies**

Neutral

**d) Ensure better patient selection/stratification**

Neutral

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Neutral

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

**First Priority**

b) Promote development of non-pharmacological interventions

**Second Priority**

a) Increase involvement of individuals in research

**Third Priority**

c) Conduct multi-centre primary prevention studies

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

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

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

## Disease cause, mechanisms and models

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

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

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Agree

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

Agree

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

Agree

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

Neutral

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

Agree

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

Neutral

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

**First Priority**

a) Understand relationship between NDD and ageing

**Second Priority**

**Third Priority**

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

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

## Diagnosis, disease definitions and outcome measures

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

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

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

## Data, registries, repositories and centres

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

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

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

- First Priority
- Second Priority
- Third Priority

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

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

- First Priority
- Second Priority
- Third Priority

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

## Funding and funding mechanisms

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

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

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

**First Priority**

**Second Priority**

**Third Priority**

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

## **Concluding questions**

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

[The most effective physical / rehabilitation approaches to use with people with NDD](#)

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

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

**UID**

1795

**Title**

Dr

**First Name**

Anne

**Surname**

Ekdahl

**Category of respondee**

Healthcare professional - Geriatrician

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

Swedish Association of Geriatric Medicine

**Country**

Sweden

## Education, training and collaboration

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

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

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

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

Neutral

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

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

b) Improve education and training of healthcare professionals

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

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

## Health and social care issues

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

**a) Define the term "care"**

Agree

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

Strongly Agree

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

Strongly Agree

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

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

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

Agree

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

Agree

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

**First Priority**

f) Understand and investigate influence of comorbidities on NDD

**Second Priority**

c) Research into the needs of carers

**Third Priority**

d) Research end of life decision making

**Question 3: How would you define "care"?**

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

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

More focus on quality of life in terms of feeling of safety, possibility to social contacts, having a meaningful time, individualised care.

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

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

## Prevention/treatment strategies and trials

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

**a) Increase involvement of individuals in research**

Neutral

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

Agree

**c) Conduct multi-centre primary prevention studies**

Agree

**d) Ensure better patient selection/stratification**

Agree

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Agree

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

**First Priority**

d) Ensure better patient selection/stratification

**Second Priority**

b) Promote development of non-pharmacological interventions

**Third Priority**

e) Rethink approach to therapeutics

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

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

## Disease cause, mechanisms and models

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

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

Agree

**b) Improve understanding of disease stages**

Agree

**c) Improve understanding of disease mechanisms**

Agree

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

Agree

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

Strongly Agree

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

Disagree

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

Agree

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

Neutral

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

**First Priority**

**Second Priority**

**Third Priority**

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

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

## Diagnosis, disease definitions and outcome measures

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

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

Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Agree

**c) Develop new biomarkers**

Neutral

**d) Consider regulatory approaches**

Neutral

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

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

## Data, registries, repositories and centres

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

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

Agree

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

Agree

**c) Improve data and sample collection**

Agree

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

Agree

**e) Develop centres of excellence**

Agree

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

**First Priority**

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

**Second Priority**

**Third Priority**

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

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

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

## Policy, regulation and legislation

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

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

Agree

**b) Ensure greater engagement with regulators**

Agree

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

Agree

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

Agree

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

Agree

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

Agree

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

Neutral

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

**First Priority**

**Second Priority**

**Third Priority**

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

## Funding and funding mechanisms

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

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

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

**First Priority**

d) Simplify funding application systems

**Second Priority**

**Third Priority**

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

## **Concluding questions**

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

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

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

**UID**

1894

**Title**

Dr

**First Name**

Arturo

**Surname**

Vilches-Moraga

**Category of respondee**

Healthcare professional - Geriatrician

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

Sociedad Española de Geriatria y Gerontología

**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**

Strongly Agree

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

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

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

b) Improve education and training of healthcare professionals

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

Neurology, Psychiatry, Neuroscience

## 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**

**Second Priority**

**Third Priority**

**Question 3: How would you define "care"?**

Resolve and meet the needs of patients in social, psychological and health especially, in a quiet and safe environment closely with the family and main caregiver

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

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

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

## Prevention/treatment strategies and trials

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

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

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

**First Priority**

- b) Promote development of non-pharmacological interventions

**Second Priority**

- e) Rethink approach to therapeutics

**Third Priority**

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

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

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

## Disease cause, mechanisms and models

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

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

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

**First Priority**

- a) Understand relationship between NDD and ageing

**Second Priority**

- c) Improve understanding of disease mechanisms

**Third Priority**

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

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

- c) Mechanisms of neuronal death and dysfunction

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

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

## Diagnosis, disease definitions and outcome measures

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

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

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

- a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

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

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

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

**First Priority**

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

**Second Priority**

**Third Priority**

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

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

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

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

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

## Policy, regulation and legislation

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

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

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

**First Priority**

- 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**  
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**

- a) Translational research needs to be promoted

**Second Priority**

**Third Priority**

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

## **Concluding questions**

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

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

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

**UID**

1907

**Title**

Dr

**First Name**

Frederic

**Surname**

Blanc

**Category of respondee**

Healthcare professional - Neurologist

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

University Hospital of Strasbourg

**Country**

France

## Education, training and collaboration

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

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

Agree

**b) Improve education and training of healthcare professionals**

Agree

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

Agree

**d) Increase training for translational and clinician-scientists**

Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

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

d) Increase training for translational and clinician-scientists

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

## Health and social care issues

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

**a) Define the term "care"**

Neutral

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

Agree

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

Agree

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

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

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

Agree

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

Agree

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

**First Priority**

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

**Second Priority**

f) Understand and investigate influence of comorbidities on NDD

**Third Priority**

g) Conduct research into effects of nutrition and frailty

**Question 3: How would you define "care"?**

Strength lives capable of surrounding, of supporting and of helping

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

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

## Prevention/treatment strategies and trials

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

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

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

**First Priority**

- d) Ensure better patient selection/stratification

**Second Priority**

- e) Rethink approach to therapeutics

**Third Priority**

- a) Increase involvement of individuals in research

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

The first step is to promote such research to the medical doctors (they are often "afraid" to propose such research). More information to this population is of importance. The second step is to include the associations of patients and caregivers that can help to promote such research. The third steps could be advertisements for general population.

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

- Air pollution
- Water pollution
- Radioactivity?
- Rare and frequent infections

## Disease cause, mechanisms and models

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

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

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

**First Priority**

- a) Understand relationship between NDD and ageing

**Second Priority**

- g) Establish pan-European population-based studies

**Third Priority**

- b) Improve understanding of disease stages

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

- b) Neuronal inflammation

**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**

It is of high importance because animal models have too many limitations. I don't see any limitations of such cell-based models.

## Diagnosis, disease definitions and outcome measures

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

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

Strongly Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Strongly Agree

**d) Consider regulatory approaches**

Agree

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

a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

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

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

Strongly Agree

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

Agree

**c) Improve data and sample collection**

Agree

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

Strongly Agree

**e) Develop centres of excellence**

Agree

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

**First Priority**

d) Develop a register of persons with cognitive impairment

**Second Priority**

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

**Third Priority**

b) Improve access to patient groups, samples and data

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

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

Open access is a necessity +++.

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

The existence of few centres of excellence (for example one or two in each country) can diminish the global performance of the system because there is also a need of proximity with the patients. A centre of excellence with a specificity in each European region of 5 million of inhabitants could be a solution.

## Policy, regulation and legislation

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

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

Agree

**b) Ensure greater engagement with regulators**

Strongly Agree

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

Strongly Agree

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

Agree

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

Agree

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

Agree

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

Neutral

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

**First Priority**

a) Need for evidence-based policy

**Second Priority**

b) Ensure greater engagement with regulators

**Third Priority**

d) Encourage industry to adopt pre-competitive approach

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

## Funding and funding mechanisms

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

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

Strongly Agree

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

Strongly Agree

**c) Joint academic-industry funding models**

Strongly Agree

**d) Simplify funding application systems**

Strongly Agree

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

Strongly Agree

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

**First Priority**

a) Translational research needs to be promoted

**Second Priority**

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

**Third Priority**

b) Encourage open-access sharing of data and materials

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

## Concluding questions

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

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

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

**UID**

1930

**Title**

Dr

**First Name**

Colin

**Surname**

Doherty

**Category of respondee**

Healthcare professional - Physician

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

St James's Hospital/Trinity College Dublin

**Country**

Ireland

## Education, training and collaboration

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

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

Agree

**b) Improve education and training of healthcare professionals**

Agree

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

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

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

d) Increase training for translational and clinician-scientists

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

## Health and social care issues

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

**a) Define the term "care"**

Strongly Agree

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

Strongly Agree

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

Strongly Agree

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

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

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

Agree

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

Strongly Agree

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

**First Priority**

h) Determine cost-effectiveness of healthcare pathways

**Second Priority**

e) Rethink approaches to care

**Third Priority**

a) Define the term "care"

**Question 3: How would you define "care"?**

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

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

## Prevention/treatment strategies and trials

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

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

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

**First Priority**

- c) Conduct multi-centre primary prevention studies

**Second Priority**

- b) Promote development of non-pharmacological interventions

**Third Priority**

- e) Rethink approach to therapeutics

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

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

## Disease cause, mechanisms and models

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

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

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

**First Priority**

- c) Improve understanding of disease mechanisms

**Second Priority**

- g) Establish pan-European population-based studies

**Third Priority**

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

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

- c) Mechanisms of neuronal death and dysfunction

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

## Diagnosis, disease definitions and outcome measures

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

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

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

- a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

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

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

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

**First Priority**

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

**Second Priority**

- c) Improve data and sample collection

**Third Priority**

- d) Develop a register of persons with cognitive impairment

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

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

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

## Policy, regulation and legislation

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

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

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

**First Priority**

- a) Need for evidence-based policy

**Second Priority**

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

**Third Priority**

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

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

## Funding and funding mechanisms

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

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

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

**First Priority**

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

**Second Priority**

- c) Joint academic-industry funding models

**Third Priority**

- a) Translational research needs to be promoted

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

## Concluding questions

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

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

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

**UID**

1995

**Title**

Dr

**First Name**

Andrea

**Surname**

Fabbo

**Category of respondee**

Healthcare professional - Geriatrician

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

Azienda Unita' Sanitaria Locale Di Modena

**Country**

Italy

## Education, training and collaboration

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

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

Agree

**b) Improve education and training of healthcare professionals**

Agree

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

Agree

**d) Increase training for translational and clinician-scientists**

Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

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

b) Improve education and training of healthcare professionals

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

Psychosocial interventions

## Health and social care issues

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

**a) Define the term "care"**

Agree

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

Neutral

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

Agree

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

Neutral

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

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

Agree

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

Agree

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

**First Priority**

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

**Second Priority**

a) Define the term 'care'

**Third Priority**

d) Research end of life decision making

**Question 3: How would you define "care"?**

As a global process that involves every dimension of person

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

Priority to chronic diseases

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

Dehospitalization

## Prevention/treatment strategies and trials

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

- a) Increase involvement of individuals in research
- b) Promote development of non-pharmacological interventions

Agree

- c) Conduct multi-centre primary prevention studies

Agree

- d) Ensure better patient selection/stratification

Agree

- e) Rethink approach to therapeutics

Agree

- f) Support for high-risk projects

Agree

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

**First Priority**

- b) Promote development of non-pharmacological interventions

**Second Priority**

- d) Ensure better patient selection/stratification

**Third Priority**

- a) Increase involvement of individuals in research

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

I dont' know

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

Quality of life, well-being

## Disease cause, mechanisms and models

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

- a) Understand relationship between neurodegenerative disease and ageing

Agree

- b) Improve understanding of disease stages

Agree

- c) Improve understanding of disease mechanisms

Neutral

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

Neutral

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

Agree

- f) Focus research on rare hereditary forms of disease

Neutral

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

Agree

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

Neutral

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

**First Priority**

- b) Improve understanding of disease stages

**Second Priority**

- a) Understand relationship between NDD and ageing

**Third Priority**

- c) Improve understanding of disease mechanisms

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

- d) The biological basis of behavioural and psychological symptoms

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

## Diagnosis, disease definitions and outcome measures

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

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

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

- a) **Linking to the mechanism of disease and functional endpoints**

## Data, registries, repositories and centres

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

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

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

**First Priority**

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

**Second Priority**

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

**Third Priority**

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

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

- Communication and information

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

- The progression of the study

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

- YES

## Policy, regulation and legislation

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

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

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

**First Priority**

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

**Second Priority**

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?**

Diffusion of research in Health system

## **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**

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**

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)**

Communication and participation

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

Participation and inclusion in research of public health system

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

UID

2018

Title

Dr.

First Name

Ruth

Surname

Veenhuizen

Category of respondee

Healthcare professional - Elderly Care physician

Replying on behalf of organisation/company?

Yes

Institution/Organisation/Company

Zorggroep Noorderbreedte, Leeuwarden

Country

Netherlands

## Education, training and collaboration

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

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

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

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

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

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

d) Increase training for translational and clinician-scientists

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

The efficacy of psychosocial therapies in comparison with medication

## Health and social care issues

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

**a) Define the term "care"**

Agree

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

Agree

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

Agree

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

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Neutral

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

Agree

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

Agree

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

**First Priority**

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

**Second Priority**

c) Research into the needs of carers

**Third Priority**

e) Rethink approaches to care

**Question 3: How would you define "care"?**

Care is the complete support on the physical, mental and social domains of diseases or handicaps and 'Care' includes diagnosis, cure, therapy, assisted living, palliation.

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

Care systems should overview the total content of disease specific pathways (including symptoms, diagnostic strategies, treatment, homecare, adapting to disabilities, palliation) Integration in care pathways

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

Organising good coordination of care at home by specialist nurses who can overview the complete pathway and have multidisciplinary backup from specialists.

## Prevention/treatment strategies and trials

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

**a) Increase involvement of individuals in research**

Strongly Agree

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

Strongly Agree

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Agree

**e) Rethink approach to therapeutics**

Strongly Agree

**f) Support for high-risk projects**

Strongly Agree

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

**First Priority**

b) Promote development of non-pharmacological interventions

**Second Priority**

e) Rethink approach to therapeutics

**Third Priority**

c) Conduct multi-centre primary prevention studies

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

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

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

I think we're not yet in that position

## Disease cause, mechanisms and models

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

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

Neutral

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Agree

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

Agree

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

Agree

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

Strongly Agree

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

Agree

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

Strongly Agree

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

**First Priority**

c) Improve understanding of disease mechanisms

**Second Priority**

b) Improve understanding of disease stages

**Third Priority**

g) Establish pan-European population-based studies

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

d) The biological basis of behavioural and psychological symptoms

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

No

## Diagnosis, disease definitions and outcome measures

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

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

Strongly Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Strongly Agree

**d) Consider regulatory approaches**

Agree

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

b) Linking to treatment responses

## Data, registries, repositories and centres

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

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

Strongly Agree

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

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

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

Agree

**e) Develop centres of excellence**

Strongly Agree

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

**First Priority**

e) Develop centres of excellence

**Second Priority**

b) Improve access to patient groups, samples and data

**Third Priority**

d) Develop a register of persons with cognitive impairment

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

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

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

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

There are always risks, but to my opinion the advantages can be bigger, depending how these centres work. One thing that bothers me is the accessibility of these centres for patients living in remote areas. Another risk may be that local health care professionals feel less responsible because the patient is seen by the centre of excellence

## Policy, regulation and legislation

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

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

Strongly Agree

**b) Ensure greater engagement with regulators**

Strongly Agree

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

Strongly Agree

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

Neutral

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

Agree

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

Agree

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

Agree

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

**First Priority**

a) Need for evidence-based policy

**Second Priority**

c) Facilitate research in areas outside university and hospital sectors

**Third Priority**

g) Review and update legislation on privacy and data disclosure

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

## Funding and funding mechanisms

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

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

Strongly Agree

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

Agree

**c) Joint academic-industry funding models**

Disagree

**d) Simplify funding application systems**

Agree

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

Agree

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

**First Priority**

a) Translational research needs to be promoted

**Second Priority**

c) Joint academic-industry funding models

**Third Priority**

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

## Concluding questions

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

Promote interacting with lay organisation to improve efficacy and need-based research

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

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

**UID**

2080

**Title**

Dr

**First Name**

Mariachiara

**Surname**

Sensi

**Category of respondee**

Healthcare professional - Neurologist

**Replying on behalf of organisation/company?**

Yes

**Institution/Organisation/Company**

Opsedale S.Anna Ferrara

**Country**

Italy

## Education, training and collaboration

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

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

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

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

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Neutral

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

d) Increase training for translational and clinician-scientists

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

no

## Health and social care issues

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

**a) Define the term "care"**

Disagree

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

Agree

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

Agree

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

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

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

Agree

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

Agree

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

**First Priority**

c) Research into the needs of carers

**Second Priority**

f) Understand and investigate influence of comorbidities on NDD

**Third Priority**

h) Determine cost-effectiveness of healthcare pathways

**Question 3: How would you define "care"?**

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

no

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

## **Prevention/treatment strategies and trials**

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

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

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

**First Priority**

- b) Promote development of non-pharmacological interventions

**Second Priority**

- c) Conduct multi-centre primary prevention studies

**Third Priority**

- d) Ensure better patient selection/stratification

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

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

## **Disease cause, mechanisms and models**

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

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

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

**First Priority**

- g) Establish pan-European population-based studies

**Second Priority**

- c) Improve understanding of disease mechanisms

**Third Priority**

- d) Develop an improved understanding of the genetic basis

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

- c) Mechanisms of neuronal death and dysfunction

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

## **Diagnosis, disease definitions and outcome measures**

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

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

Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Agree

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Agree

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

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

## Data, registries, repositories and centres

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

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

Agree

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

Agree

**c) Improve data and sample collection**

Agree

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

Agree

**e) Develop centres of excellence**

Strongly Agree

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

**First Priority**

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

**Second Priority**

e) Develop centres of excellence

**Third Priority**

b) Improve access to patient groups, samples and data

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

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

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

## Policy, regulation and legislation

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

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

Agree

**b) Ensure greater engagement with regulators**

Agree

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

Agree

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

Neutral

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

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

Agree

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

Agree

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

**First Priority**

c) Facilitate research in areas outside university and hospital sectors

**Second Priority**

f) Review and update legislation on treatment

**Third Priority**

c) Facilitate research in areas outside university and hospital sectors

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

## Funding and funding mechanisms

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

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

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

**First Priority**

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

**Second Priority**

- a) Translational research needs to be promoted

**Third Priority**

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

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

## Concluding questions

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

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

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

UID

2060

**Category of respondee**

Healthcare professional – Neurologist

**Replying on behalf of organisation/company?**

Yes

**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**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

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

a) Improve dialogue between researchers and wider population

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

## Health and social care issues

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

**a) Define the term "care"**

Agree

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

Agree

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

Agree

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

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Neutral

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

Neutral

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

Neutral

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

**First Priority**

c) Research into the needs of carers

**Second Priority**

d) Research end of life decision making

**Third Priority**

e) Rethink approaches to care

**Question 3: How would you define "care"?**

provision of support, including physical, medical, emotional and psychological to an individual from one or a team of people to improve the quality of their life and support their ongoing independence.

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

need to take age into account. huge difference between the majority population - over 80, typical AD patient and the young onset patient with a familial disorder, whether it be AD or MND-FTD

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

## Prevention/treatment strategies and trials

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

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

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

**First Priority**

- a) Increase involvement of individuals in research

**Second Priority**

- c) Conduct multi-centre primary prevention studies

**Third Priority**

- f) Support for high-risk projects

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

make it a normal part of the culture of a clinic appointment to discuss research and to discuss brain donation.

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

## Disease cause, mechanisms and models

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

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

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

**First Priority**

- g) Establish pan-European population-based studies

**Second Priority**

- c) Improve understanding of disease mechanisms

**Third Priority**

- b) Improve understanding of disease stages

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

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

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

## Diagnosis, disease definitions and outcome measures

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

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

Agree

c) **Develop new biomarkers**

Agree

d) **Consider regulatory approaches**

Neutral

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

a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

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

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

Strongly Agree

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

Strongly Agree

c) **Improve data and sample collection**

Strongly Agree

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

Strongly Agree

e) **Develop centres of excellence**

Strongly Agree

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

**First Priority**

e) Develop centres of excellence

**Second Priority**

d) Develop a register of persons with cognitive impairment

**Third Priority**

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

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

reduce competition and incentivise collaboration by sharing activity based funding and research kudos

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

large ethical difficulties

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

disenfranchising smaller groups and funnelling clinical care into those COE only will de-skill others

## Policy, regulation and legislation

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

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

b) **Ensure greater engagement with regulators**

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

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

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

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

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

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

**First Priority**

**Second Priority**

**Third Priority**

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

## Funding and funding mechanisms

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

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

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

c) **Joint academic-industry funding models**

d) **Simplify funding application systems**

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

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

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

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

## **Concluding questions**

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

no

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

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

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

**UID**

1580

**Title**

Professor

**First Name**

Desmond

**Surname**

O'Neill

**Category of respondee**

Healthcare professional - Geriatrician

**Replying on behalf of organisation/company?**

No

**Country**

Ireland

## Education, training and collaboration

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

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

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

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

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

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

b) Improve education and training of healthcare professionals

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

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

## Health and social care issues

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

**a) Define the term "care"**

Agree

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

Strongly Agree

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

Neutral

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

Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

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

Agree

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

Strongly Agree

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

**First Priority**

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

**Second Priority**

f) Understand and investigate influence of comorbidities on NDD

**Third Priority**

e) Rethink approaches to care

**Question 3: How would you define "care"?**

The application of the biopsychosocial model to assess need, and provide therapeutic, rehabilitative and support measures to maintain quality of life and health of the person affected by the neurological disease and those providing informal support

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

Universal application of key gerontological competence provides the substrate for better care of those with neurodegenerative illnesses

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

Agreed definition of assessment, gerontological attuning of health-care system, rights-based approach prioritizing the needs and wish of the person affected

## Prevention/treatment strategies and trials

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

**a) Increase involvement of individuals in research**

Strongly Agree

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

Strongly Agree

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Disagree

**e) Rethink approach to therapeutics**

Strongly Agree

**f) Support for high-risk projects**

Agree

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

**First Priority**

e) Rethink approach to therapeutics

**Second Priority**

a) Increase involvement of individuals in research

**Third Priority**

c) Conduct multi-centre primary prevention studies

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

Better training of healthcare staff, better public diffusion of benefits of research

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

Lifestyle - exercise, blood pressure, smoking

## Disease cause, mechanisms and models

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

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

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

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

Agree

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

Strongly Agree

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

Disagree

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

Strongly Agree

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

Agree

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

**First Priority**

a) Understand relationship between NDD and ageing

**Second Priority**

c) Improve understanding of disease mechanisms

**Third Priority**

g) Establish pan-European population-based studies

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

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

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

No

## Diagnosis, disease definitions and outcome measures

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

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

Strongly Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Strongly Agree

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

d) Facilitating back-translation to models of disease

## Data, registries, repositories and centres

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

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

Strongly Agree

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

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

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

Strongly Agree

**e) Develop centres of excellence**

Neutral

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

**First Priority**

b) Improve access to patient groups, samples and data

**Second Priority**

d) Develop a register of persons with cognitive impairment

**Third Priority**

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

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

Common clinical database, anonymized

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

Positive, data protection and security key issues

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

Tends to institutionalize and sclerose existing relationships, losing flexibility and access to a wider range of talent. Suggest networks of excellence

## Policy, regulation and legislation

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

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

Strongly Agree

**b) Ensure greater engagement with regulators**

Agree

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

Strongly Agree

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

Agree

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

Neutral

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

Agree

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

Strongly Agree

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

**First Priority**

a) Need for evidence-based policy

**Second Priority**

c) Facilitate research in areas outside university and hospital sectors

**Third Priority**

b) Ensure greater engagement with regulators

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

## Funding and funding mechanisms

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

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

Agree

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

Strongly Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

Strongly Agree

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

Strongly Agree

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

**First Priority**

b) Encourage open-access sharing of data and materials

**Second Priority**

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

**Third Priority**

d) Simplify funding application systems

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

## Concluding questions

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

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

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

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

**UID**

1586

**Title**

Dr

**First Name**

Tayyeb

**Surname**

Tahir

**Category of respondee**

Healthcare professional - Liaison Psychiatrist

**Replying on behalf of organisation/company?**

No

**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?**

e) Increase numbers of post-doctoral researchers

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

Treatment and Management of Delirium in general hospital

## Health and social care issues

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

**a) Define the term "care"**

Agree

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

Neutral

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

Agree

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

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

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

Strongly Agree

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

Strongly Agree

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

**First Priority**

f) Understand and investigate influence of comorbidities on NDD

**Second Priority**

g) Conduct research into effects of nutrition and frailty

**Third Priority**

h) Determine cost-effectiveness of healthcare pathways

**Question 3: How would you define "care"?**

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

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

## Prevention/treatment strategies and trials

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

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

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

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

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

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

## Disease cause, mechanisms and models

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

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

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

- First Priority**
  - a) Understand relationship between NDD and ageing
- Second Priority**
  - d) Develop an improved understanding of the genetic basis
- Third Priority**
  - b) Improve understanding of disease stages

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

- d) The biological basis of behavioural and psychological symptoms

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

## Diagnosis, disease definitions and outcome measures

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

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

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Agree

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

b) Linking to treatment responses

## Data, registries, repositories and centres

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

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

Strongly Agree

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

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

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

Strongly Agree

**e) Develop centres of excellence**

Strongly Agree

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

**First Priority**

**Second Priority**

**Third Priority**

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

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

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

## Policy, regulation and legislation

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

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

Agree

**b) Ensure greater engagement with regulators**

Agree

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

Agree

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

Agree

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

Agree

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

Agree

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

Agree

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

**First Priority**

**Second Priority**

**Third Priority**

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

## Funding and funding mechanisms

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

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

Agree

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

Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

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**

**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**

1621

**Title**

Professor

**First Name**

Koen

**Surname**

Van Laere

**Category of respondee**

Healthcare professional - Nuclear Medicine

**Replying on behalf of organisation/company?**

No

**Country**

Belgium

## Education, training and collaboration

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

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

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

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

**d) Increase training for translational and clinician-scientists**

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

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

d) Increase training for translational and clinician-scientists

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

## Health and social care issues

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

**a) Define the term "care"**

Neutral

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

Agree

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

Neutral

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

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

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

Neutral

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

Strongly Agree

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

**First Priority**

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

**Second Priority**

h) Determine cost-effectiveness of healthcare pathways

**Third Priority**

f) Understand and investigate influence of comorbidities on NDD

**Question 3: How would you define "care"?**

Support on a medical, social and psychological basis.

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

-

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

-

## Prevention/treatment strategies and trials

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

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

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

**First Priority**

- a) Increase involvement of individuals in research

**Second Priority**

- d) Ensure better patient selection/stratification

**Third Priority**

- f) Support for high-risk projects

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

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

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

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

## Disease cause, mechanisms and models

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

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

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

**First Priority**

- a) Understand relationship between NDD and ageing

**Second Priority**

- c) Improve understanding of disease mechanisms

**Third Priority**

- g) Establish pan-European population-based studies

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

- c) Mechanisms of neuronal death and dysfunction

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

Yes. Imaging of biomarkers and their development, concerning targets that can be defined on the cellular level (eg amyloid, tau, alphasynuclein...), and where animal models are not very predictive for human findings.

## Diagnosis, disease definitions and outcome measures

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

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

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

- a) **Linking to the mechanism of disease and functional endpoints**

## Data, registries, repositories and centres

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

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

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

**First Priority**

- e) **Develop centres of excellence**

**Second Priority**

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

**Third Priority**

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

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

- obligatory registration and database entry of ongoing trials

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

- dependent on financial investments put into these. inclusion of pharmaceutical industry ?

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

- sufficient and critical appraisal and evaluation of performance

## Policy, regulation and legislation

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

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

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

**First Priority**

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

**Second Priority**

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

### Third Priority

- a) Need for evidence-based policy

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

## Funding and funding mechanisms

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

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

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

#### First Priority

- d) Simplify funding application systems

#### Second Priority

- c) Joint academic-industry funding models

#### Third Priority

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

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

Europe funded studies should be obliged to make data available upon completion of project to European centres.

## Concluding questions

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

-

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

-

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

**UID**

1651

**Title**

Dr

**First Name**

Georgios

**Surname**

SPATHARAKIS

**Category of respondee**

Healthcare professional - Primary Health Care

**Replying on behalf of organisation/company?**

No

**Country**

Greece

## 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?**

b) Improve education and training of healthcare professionals

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

## Health and social care issues

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

**a) Define the term "care"**

Neutral

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

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**

Strongly Agree

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

**First Priority**

e) Rethink approaches to care

**Second Priority**

a) Define the term 'care'

**Third Priority**

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

**Question 3: How would you define "care"?**

Physical presence, interest in helping, human approach, holistic approach, respect of life, decision making, use of specialized technical support and/or skills, home adaptation, maintenance of social life, spirituality, medical care

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

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

-Training of more professionals -Support from networks (for example, Alzheimer's Societies) -Training of professional home carers -Training and psychological support of informal, family carers -Availability and low-cost, easy to use

## Prevention/treatment strategies and trials

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

**a) Increase involvement of individuals in research**

Agree

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

Strongly Agree

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Agree

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Neutral

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

**First Priority**

b) Promote development of non-pharmacological interventions

**Second Priority**

e) Rethink approach to therapeutics

**Third Priority**

c) Conduct multi-centre primary prevention studies

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

-Information of general public -Specific Information of family carers -Get agreement and Support from local churches

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

## Disease cause, mechanisms and models

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

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

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Agree

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

Agree

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

Strongly Agree

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

Neutral

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

Strongly Agree

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

Agree

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

**First Priority**

a) Understand relationship between NDD and ageing

**Second Priority**

b) Improve understanding of disease stages

**Third Priority**

e) Determine the importance of genetic and environmental risk factors

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

d) The biological basis of behavioural and psychological symptoms

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

## Diagnosis, disease definitions and outcome measures

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

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

Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Strongly Agree

**d) Consider regulatory approaches**

Agree

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

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

## Data, registries, repositories and centres

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

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

Agree

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

Agree

**c) Improve data and sample collection**

Strongly Agree

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

Strongly Agree

**e) Develop centres of excellence**

Strongly Agree

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

**First Priority**

b) Improve access to patient groups, samples and data

**Second Priority**

c) Improve data and sample collection

**Third Priority**

d) Develop a register of persons with cognitive impairment

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

-Create permissive legislation but also ensure prevention of misuse -Create data bases -Specify the profile of those who will have access

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

-data should be available on those working on the field, researchers of health professionals

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

NO

## Policy, regulation and legislation

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

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

Strongly Agree

**b) Ensure greater engagement with regulators**

Strongly Agree

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

Strongly Agree

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

Strongly Agree

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

Neutral

**f) Review and update legislation on treatment**

Neutral

**g) Review and update legislation on privacy and data disclosure**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- a) Need for evidence-based policy

**Second Priority**

- c) Facilitate research in areas outside university and hospital sectors

**Third Priority**

- e) Rethink patent lifetime and conduct public-private clinical trials

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Strongly Agree

**b) Encourage open-access sharing of data and materials**

Strongly Agree

**c) Joint academic-industry funding models**

Strongly Agree

**d) Simplify funding application systems**

Strongly Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- c) Joint academic-industry funding models

**Second Priority**

- d) Simplify funding application systems

**Third Priority**

- e) Maintain capacity for 'bottom-up' innovative funding

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

**UID**

1768

**Title**

Dr

**First Name**

Michael

**Surname**

watts

**Category of respondee**

Healthcare professional

**Replying on behalf of organisation/company?**

No

**Country**

Ireland

## Education, training and collaboration

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve dialogue between researchers and the wider population**

Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

**c) Increase numbers of neurodegenerative disease (NDD) researchers**

Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

d) Increase training for translational and clinician-scientists

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Strongly Agree

**b) Survey long-term care standards and provision across Europe**

Agree

**c) Research into the needs of carers**

Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Neutral

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Rethink approaches to care

**Second Priority**

d) Research end of life decision making

**Third Priority**

b) Survey long-term care standards and provision across Europe

**Question 3: How would you define "care"?**

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Increase involvement of individuals in research**  
Agree
- b) **Promote development of non-pharmacological interventions**  
Agree
- c) **Conduct multi-centre primary prevention studies**  
Agree
- d) **Ensure better patient selection/stratification**  
Strongly Agree
- e) **Rethink approach to therapeutics**  
Strongly Agree
- f) **Support for high-risk projects**  
Disagree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- e) Rethink approach to therapeutics

**Second Priority**

- a) Increase involvement of individuals in research

**Third Priority**

- d) Ensure better patient selection/stratification

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

## **Disease cause, mechanisms and models**

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Understand relationship between neurodegenerative disease and ageing**  
Agree
- b) **Improve understanding of disease stages**  
Neutral
- c) **Improve understanding of disease mechanisms**  
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**  
Neutral
- e) **Determine the importance of genetic and environmental risk factors**  
Agree
- f) **Focus research on rare hereditary forms of disease**  
Disagree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**  
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**  
Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- c) Improve understanding of disease mechanisms

**Second Priority**

- g) Establish pan-European population-based studies

**Third Priority**

- e) Determine the importance of genetic and environmental risk factors

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

- d) The biological basis of behavioural and psychological symptoms

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

## **Diagnosis, disease definitions and outcome measures**

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Redefine and standardise disease definitions and diagnosis**  
Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Agree

**c) Develop new biomarkers**

Neutral

**d) Consider regulatory approaches**

Neutral

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

b) Linking to treatment responses

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

Agree

**b) Improve access to patient groups, samples and data**

Neutral

**c) Improve data and sample collection**

Strongly Agree

**d) Develop a register of persons with cognitive impairment**

Strongly Agree

**e) Develop centres of excellence**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

b) Improve access to patient groups, samples and data

**Second Priority**

c) Improve data and sample collection

**Third Priority**

e) Develop centres of excellence

**Question 3: What can be done to facilitate increased sharing of data?**

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Strongly Agree

**b) Ensure greater engagement with regulators**

Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Agree

**f) Review and update legislation on treatment**

Agree

**g) Review and update legislation on privacy and data disclosure**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Facilitate research in areas outside university and hospital sectors

**Second Priority**

a) Need for evidence-based policy

**Third Priority**

g) Review and update legislation on privacy and data disclosure

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Strongly Agree

**b) Encourage open-access sharing of data and materials**

Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Translational research needs to be promoted

**Second Priority**

c) Joint academic-industry funding models

**Third Priority**

d) Simplify funding application systems

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## **Concluding questions**

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

**UID**

1893

**Title**

Dr

**First Name**

Morillas

**Surname**

Manuel

**Category of respondee**

Healthcare professional - Hospital Administrator

**Replying on behalf of organisation/company?**

No

**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**

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

**c) Increase numbers of neurodegenerative disease (NDD) researchers**

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

a) Improve dialogue between researchers and wider population

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Disagree

**b) Survey long-term care standards and provision across Europe**

Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Agree

**h) Determine cost-effectiveness of healthcare pathways**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Research into the needs of carers

**Second Priority**

b) Survey long-term care standards and provision across Europe

**Third Priority**

g) Conduct research into effects of nutrition and frailty

**Question 3: How would you define "care"?**

Care is not only given to NDD patients but also is the quality of life and stress of NDD carers. Long term diseases affect deeply carers and their exhaustion after many years of care affects the quality of the care provided, hence CARE is a wider concept

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

Health authorities do not measure effectively the cost effectiveness of CARE systems that affect NDD. More emphasis on the cost of the CARER should be done.

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

MOre economic help for CARE at home is needed, family and friends cannot cope with a patient for years, hence economic help to alleviate the burden of 24h care of a patient is needed

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Agree

**b) Promote development of non-pharmacological interventions**

Agree

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Strongly Agree

**e) Rethink approach to therapeutics**

Strongly Agree

**f) Support for high-risk projects**

Neutral

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

d) Ensure better patient selection/stratification

**Second Priority**

c) Conduct multi-centre primary prevention studies

**Third Priority**

b) Promote development of non-pharmacological interventions

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

Patients' associations should liaise more between health centres and patients and be more visible in the general society.

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

Patient stratification accordingly to their genetic and social background should be emphasized.

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Strongly Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

Strongly Agree

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Strongly Agree

**h) Develop more representative animal and cell-based models of disease**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

g) Establish pan-European population-based studies

**Second Priority**

b) Improve understanding of disease stages

**Third Priority**

e) Determine the importance of genetic and environmental risk factors

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

b) Neuronal inflammation

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

There is no justification for missing out animal models

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Agree

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

Strongly Agree

**b) Improve access to patient groups, samples and data**

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

**d) Develop a register of persons with cognitive impairment**

**e) Develop centres of excellence**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

b) Improve access to patient groups, samples and data

**Second Priority**

a) Improve access to, and sharing of, infrastructure and resources

**Third Priority**

c) Improve data and sample collection

**Question 3: What can be done to facilitate increased sharing of data?**

Greater funding for a pan European Network of Excellence that amalgamates the most relevant stakeholders (primary care centres associations, hospitals, Universities)

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Strongly Agree

**b) Ensure greater engagement with regulators**

Strongly Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Strongly Agree

**f) Review and update legislation on treatment**

Agree

**g) Review and update legislation on privacy and data disclosure**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Facilitate research in areas outside university and hospital sectors

**Second Priority**

e) Rethink patent lifetime and conduct public-private clinical trials

**Third Priority**

a) Need for evidence-based policy

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Strongly Agree

**b) Encourage open-access sharing of data and materials**

Strongly Agree

**c) Joint academic-industry funding models**

Strongly Agree

**d) Simplify funding application systems**

Strongly Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Maintain capacity for 'bottom-up' innovative funding

**Second Priority**

a) Translational research needs to be promoted

**Third Priority**

c) Joint academic-industry funding models

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

Promotion of a pan-European well funded agency that works in a coordinated homogenous manner to tackle homogeneously NDD. For instance JPND is doing a great job promoting research calls, but every country is funding the calls in a heterogeneous inefficient way. Good researchers in some countries received less fund than other researchers in the same Consortium but in other countries because each funding agency locates funds in a different way. A common fund where all Consortia compete should be encouraged.

**Question 3: Is there anything else you would like to tell us?**

**UID**

1971

**Title**

Professor

**First Name**

Rowan

**Surname**

Harwood

**Category of respondee**

Healthcare professional - Geriatrician

**Replying on behalf of organisation/company?**

No

**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?**

integration and facilitation of research and health care practice (eg modifying barriers such as restrictive data protection regulations)

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Neutral

**b) Survey long-term care standards and provision across Europe**

Agree

**c) Research into the needs of carers**

Agree

**d) Research into care approaches including end of life decision-making**

Agree

**e) Rethink approaches to care**

Neutral

**f) Understand and investigate influence of comorbidities**

Strongly Agree

**g) Conduct research into effects of nutrition and frailty**

Agree

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

h) Determine cost-effectiveness of healthcare pathways

**Second Priority**

f) Understand and investigate influence of comorbidities on NDD

**Third Priority**

c) Research into the needs of carers

**Question 3: How would you define "care"?**

interventions designed to reverse or mitigate the effects of ill-health, substitute for activity limitations, or provide support for patients or their carers

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

'vertical integration' of health and social care: we need to remove barriers between organisations and providers, and design flexible pathways that include a variety of needs (including ensuring proper access to acute hospital and long term nursing care where this is appropriate and necessary)

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

Two aspects, entitlement and decision making 1. ensuring that rigorous assessment of needs has equal prominence to cost (the most intensive home care is more costly than institutional care) 2. through a proper decision making process, such as is set out in the English mental capacity Act 2005

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Strongly Agree

**b) Promote development of non-pharmacological interventions**

Strongly Agree

**c) Conduct multi-centre primary prevention studies**

Disagree

**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**

a) Increase involvement of individuals in research

**Third Priority**

f) Support for high-risk projects

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

better integration (or mandating) of research in health care practice

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

I answered disagree to section C) because I do not believe we are in a position to conduct sensible primary prevention research (given that cardiovascular risk factor prevention is already established and uncontroversial). We need more basic epidemiology first. There are options for mitigating effects - 'tertiary prevention'

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

Disagree

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Strongly Agree

**h) Develop more representative animal and cell-based models of disease**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

g) Establish pan-European population-based studies

**Second Priority**

e) Determine the importance of genetic and environmental risk factors

**Third Priority**

c) Improve understanding of disease mechanisms

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

d) The biological basis of behavioural and psychological symptoms

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

probably not, given the need for satisfactory toxicology data (which would necessarily involve animals). However, in theory yes when it comes to assessing efficacy (given relative lack of good animal models): judge each case on its merits, and use patient and public involvement mechanisms to ensure probity

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

a) **Redefine and standardise disease definitions and diagnosis**

Neutral

b) **Redefine and harmonise clinical endpoints and outcomes**

Agree

c) **Develop new biomarkers**

Agree

d) **Consider regulatory approaches**

Neutral

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

b) Linking to treatment responses

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

a) **Improve access to, and sharing of, infrastructure and resources**

Strongly Agree

b) **Improve access to patient groups, samples and data**

Strongly Agree

c) **Improve data and sample collection**

Agree

d) **Develop a register of persons with cognitive impairment**

Strongly Agree

e) **Develop centres of excellence**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

b) Improve access to patient groups, samples and data

**Second Priority**

a) Improve access to, and sharing of, infrastructure and resources

**Third Priority**

d) Develop a register of persons with cognitive impairment

**Question 3: What can be done to facilitate increased sharing of data?**

Revision of data protection legislation eg to allow greater use of clinical (healthcare provision) data for research purposes without cumbersome consent/consultee agreement requirements

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

great in principal. Unlikely in practice given current concentration in intellectual property rights by both academic institutions and industry. Could be made a condition of public funding.

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

Development is inhibited elsewhere - a hub and spoke model may help This is especially required to get access to large numbers of patients for epidemiological studies or trials

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

a) **Need for evidence-based policy**

Agree

b) **Ensure greater engagement with regulators**

Strongly Agree

c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Strongly Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Agree

**f) Review and update legislation on treatment**

Agree

**g) Review and update legislation on privacy and data disclosure**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

g) Review and update legislation on privacy and data disclosure

**Second Priority**

c) Facilitate research in areas outside university and hospital sectors

**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?**

Money talks. UK universities are very focussed on performance indicators. This inhibits early stage, more speculative, and less methodologically developed fields of study, which are seen as less productive, and this is particularly true for NDD. Research policy makers need to circumvent this by ensuring generous project, development and training funding, and an understanding of the limitations on NDD research that can make it appear less productive or less good value for money (eg recruitment to trials of people lacking mental capacity is very time consuming and labour intensive). NDD funding needs to be ring fenced and not in open competition with cancer, cardiovascular or mainstream genomics.

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Strongly Agree

**b) Encourage open-access sharing of data and materials**

Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

Strongly Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Maintain capacity for 'bottom-up' innovative funding

**Second Priority**

d) Simplify funding application systems

**Third Priority**

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

make it a requirement of public funding (cf NIH publication rules in US)

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

patient public involvement mechanisms (but be cautious about ensuring they really do provide added value)  
Complex service delivery trial regulation and guidance (GCP does not fit well) Health Policy and health services research (these may well have greater impact on clinical practice and patient experience than you might give credit for, and offer earlier gains than more fundamental research) You mentioned co-morbidity: delirium is a special case of this which is barely understood, and might deserve special attention

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

Crucial area, horribly under-researched, keep up the good work

UID

2006

Title

Dr

First Name

Elizabeth

Surname

Coulthard

Category of respondee

Healthcare professional - Neurologist

Replying on behalf of organisation/company?

No

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?**

d) Increase training for translational and clinician-scientists

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

Improving diagnostic accuracy to facilitate appropriate channeling for treatment trials/treatments

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Neutral

**b) Survey long-term care standards and provision across Europe**

Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

**g) Conduct research into effects of nutrition and frailty**

Strongly Agree

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Research into the needs of carers

**Second Priority**

f) Understand and investigate influence of comorbidities on NDD

**Third Priority**

e) Rethink approaches to care

**Question 3: How would you define "care"?**

All aspects of patient management from initial presentation and diagnosis through treatment to end of life planning.

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

Each patient could have a named nurse who would oversee their care from start to finish.

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

Staff in care homes should be trained to care for patients with dementia and the environment and activity schedule should be targeted to the needs of each individual.

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Strongly Agree

**b) Promote development of non-pharmacological interventions**

Agree

**c) Conduct multi-centre primary prevention studies**

Agree

**d) Ensure better patient selection/stratification**

Strongly Agree

**e) Rethink approach to therapeutics**

Strongly Agree

**f) Support for high-risk projects**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Increase involvement of individuals in research

**Second Priority**

d) Ensure better patient selection/stratification

**Third Priority**

c) Conduct multi-centre primary prevention studies

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

If a clinician with whom the patient is familiar raises the issue of brain donation, the patient is more likely to consider consenting.

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Neutral

**b) Improve understanding of disease stages**

Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

Agree

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Strongly Agree

**h) Develop more representative animal and cell-based models of disease**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Improve understanding of disease mechanisms

**Second Priority**

e) Determine the importance of genetic and environmental risk factors

**Third Priority**

g) Establish pan-European population-based studies

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

c) Mechanisms of neuronal death and dysfunction

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Strongly Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Neutral

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

c) Providing an indicator of, and sensitivity to, disease progression

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

Strongly Agree

**b) Improve access to patient groups, samples and data**

Strongly Agree

**c) Improve data and sample collection**

Agree

**d) Develop a register of persons with cognitive impairment**

Agree

**e) Develop centres of excellence**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Improve access to, and sharing of, infrastructure and resources

**Second Priority**

b) Improve access to patient groups, samples and data

**Third Priority**

d) Develop a register of persons with cognitive impairment

**Question 3: What can be done to facilitate increased sharing of data?**

Encourage uploading of research methodology and data to a secure, user-friendly, web-based system.

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

Data should be open access once anonymised after the author has published the results (unless there is no plan to publish).

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

Smaller centres could be marginalised and this could limit the degree of ingenuity in research as strong research themes within a centre of excellence dominate. Dementia patients may have to travel further to a centre of excellence. It would be better to have more centres close to patients with rigorous standards applied to ensure excellence.

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Strongly Agree

**b) Ensure greater engagement with regulators**

Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Neutral

**f) Review and update legislation on treatment**

Agree

**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**

c) Facilitate research in areas outside university and hospital sectors

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Strongly Agree

**b) Encourage open-access sharing of data and materials**

Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

Neutral

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Translational research needs to be promoted

**Second Priority**

e) Maintain capacity for 'bottom-up' innovative funding

**Third Priority**

c) Joint academic-industry funding models

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

We have used ADNI data and found this a useful means of resource sharing.

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

**UID**

2034

**Title**

Dr

**First Name**

Nenad

**Surname**

Bogdanovic

**Category of respondee**

Healthcare professional - Geriatrician

**Replying on behalf of organisation/company?**

No

**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?**

aging, cognitive impairment, early assesment , dementia

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Neutral

**b) Survey long-term care standards and provision across Europe**

Strongly Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

**g) Conduct research into effects of nutrition and frailty**

Strongly Agree

**h) Determine cost-effectiveness of healthcare pathways**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Rethink approaches to care

**Second Priority**

a) Define the term 'care'

**Third Priority**

c) Research into the needs of carers

**Question 3: How would you define "care"?**

A comprehensive and disease-specific professional and nonprofessional medical and social support for patient to maintain a high quality of life and to decrease suffering

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

patient and caregiver friendly, revision of local and country policy , introducing the innovation technology , education of the population from the elementary school to understand what is a care for closest

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

to stimulate home care, introducing an innovative technology, increase the time spending for caregivers, education of caregivers, individual-oriented home adaptation. Accessibility to health professionals. Full social engagement

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Strongly Agree

**b) Promote development of non-pharmacological interventions**

Strongly Agree

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Strongly Agree

**e) Rethink approach to therapeutics**

Strongly Agree

**f) Support for high-risk projects**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Increase involvement of individuals in research

**Second Priority**

d) Ensure better patient selection/stratification

**Third Priority**

e) Rethink approach to therapeutics

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

education education education of health professionals. changing negative attitude of health professionals towards postmortem analysis, early discussion with patients and caregivers regarding importance of research. To have a very clear position that there is no animal model for human neurodegenerative diseases

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

to educate and inform population and HPs of importance. To increase an awareness of political structures on local or country level

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Strongly Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

**h) Develop more representative animal and cell-based models of disease**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Understand relationship between NDD and ageing

**Second Priority**

c) Improve understanding of disease mechanisms

**Third Priority**

b) Improve understanding of disease stages

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

a) Interactions between cells and their surrounding intra- and extracellular environment

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

NO animal model to date that can mimic neurodegeneration in humans

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Strongly Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Strongly Agree

**d) Consider regulatory approaches**

Disagree

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

**b) Improve access to patient groups, samples and data**

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

**d) Develop a register of persons with cognitive impairment**

Strongly Agree

**e) Develop centres of excellence**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Improve access to, and sharing of, infrastructure and resources

**Second Priority**

b) Improve access to patient groups, samples and data

**Third Priority**

e) Develop centres of excellence

**Question 3: What can be done to facilitate increased sharing of data?**

increase a protection of data

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

important to keep privacy

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

only if center of excellence will not serve as an educational hub for entire professional and non-professional community

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Agree

**b) Ensure greater engagement with regulators**

Strongly Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Strongly Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Strongly Agree

**f) Review and update legislation on treatment**

Agree

**g) Review and update legislation on privacy and data disclosure**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

g) Review and update legislation on privacy and data disclosure

**Second Priority**

c) Facilitate research in areas outside university and hospital sectors

**Third Priority**

d) Encourage industry to adopt pre-competitive approach

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

increase fundings, decrease military budgets, regruting high professional experts in regulatory agencies

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Strongly Agree

**b) Encourage open-access sharing of data and materials**

Strongly Agree

**c) Joint academic-industry funding models**

Strongly Agree

**d) Simplify funding application systems**

Strongly Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Joint academic-industry funding models

**Second Priority**

d) Simplify funding application systems

**Third Priority**

e) Maintain capacity for 'bottom-up' innovative funding

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

to build up transregional network programs

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

permanent education of policy makers    aging is not problem of aged people only    but entire society  
harmonization and synchronization of clinical and preclinical knowledge

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

Ad 1) despite different political opinions, health should not be polarised. Trying to find the best solutions that are patient-friendly. Politician should be open for education and should listen professionals    Ad2) education from kindergarden level what

**Question 3: Is there anything else you would like to tell us?**

yes but there is not enough place

**UID**

2135

**Title**

Dr

**First Name**

Ales

**Surname**

Kogoj

**Category of respondee**

Healthcare professional - Psychiatrist

**Replying on behalf of organisation/company?**

No

**Country**

Slovenia

## Education, training and collaboration

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve dialogue between researchers and the wider population**

Agree

**b) Improve education and training of healthcare professionals**

Agree

**c) Increase numbers of neurodegenerative disease (NDD) researchers**

Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

c) Increase overall numbers of researchers

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Agree

**b) Survey long-term care standards and provision across Europe**

Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Agree

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Research into the needs of carers

**Second Priority**

d) Research end of life decision making

**Third Priority**

e) Rethink approaches to care

**Question 3: How would you define "care"?**

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Increase involvement of individuals in research**  
Agree
- b) **Promote development of non-pharmacological interventions**  
Agree
- c) **Conduct multi-centre primary prevention studies**  
Agree
- d) **Ensure better patient selection/stratification**  
Agree
- e) **Rethink approach to therapeutics**  
Agree
- f) **Support for high-risk projects**  
Neutral

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- a) Increase involvement of individuals in research

**Second Priority**

- c) Conduct multi-centre primary prevention studies

**Third Priority**

- e) Rethink approach to therapeutics

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

## **Disease cause, mechanisms and models**

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Understand relationship between neurodegenerative disease and ageing**  
Strongly Agree
- b) **Improve understanding of disease stages**  
Agree
- c) **Improve understanding of disease mechanisms**  
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**  
Agree
- e) **Determine the importance of genetic and environmental risk factors**  
Agree
- f) **Focus research on rare hereditary forms of disease**  
Agree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**  
Agree
- h) **Develop more representative animal and cell-based models of disease**  
Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- c) Improve understanding of disease mechanisms

**Second Priority**

- a) Understand relationship between NDD and ageing

**Third Priority**

- e) Determine the importance of genetic and environmental risk factors

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

- a) Interactions between cells and their surrounding intra- and extracellular environment

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

## **Diagnosis, disease definitions and outcome measures**

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Redefine and standardise disease definitions and diagnosis**  
Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Agree

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Agree

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

b) Linking to treatment responses

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

Strongly Agree

**b) Improve access to patient groups, samples and data**

Agree

**c) Improve data and sample collection**

Agree

**d) Develop a register of persons with cognitive impairment**

Agree

**e) Develop centres of excellence**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Improve access to, and sharing of, infrastructure and resources

**Second Priority**

b) Improve access to patient groups, samples and data

**Third Priority**

c) Improve data and sample collection

**Question 3: What can be done to facilitate increased sharing of data?**

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Neutral

**b) Ensure greater engagement with regulators**

Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Neutral

**f) Review and update legislation on treatment**

Agree

**g) Review and update legislation on privacy and data disclosure**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

d) Encourage industry to adopt pre-competitive approach

**Second Priority**

f) Review and update legislation on treatment

**Third Priority**

c) Facilitate research in areas outside university and hospital sectors

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Agree

**b) Encourage open-access sharing of data and materials**

Strongly Agree

**c) Joint academic-industry funding models**

Strongly Agree

**d) Simplify funding application systems**

Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

b) Encourage open-access sharing of data and materials

**Second Priority**

c) Joint academic-industry funding models

**Third Priority**

a) Translational research needs to be promoted

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## **Concluding questions**

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

**UID**

2157

**Title**

Professor

**First Name**

Timothy

**Surname**

Lynch

**Category of respondee**

Healthcare professional - Neurologist

**Replying on behalf of organisation/company?**

No

**Country**

Ireland

## Education, training and collaboration

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve dialogue between researchers and the wider population**

Strongly Agree

**b) Improve education and training of healthcare professionals**

Agree

**c) Increase numbers of neurodegenerative disease (NDD) researchers**

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

a) Improve dialogue between researchers and wider population

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

Getting the populations and politicians to understand the basics of clinical neuroscience is vital - it will put neuroscience up the agenda for funding

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Neutral

**b) Survey long-term care standards and provision across Europe**

Agree

**c) Research into the needs of carers**

Agree

**d) Research into care approaches including end of life decision-making**

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Agree

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

f) Understand and investigate influence of comorbidities on NDD

**Second Priority**

g) Conduct research into effects of nutrition and frailty

**Third Priority**

h) Determine cost-effectiveness of healthcare pathways

**Question 3: How would you define "care"?**

The process of looking after a patient and/or carer - includes nursing, medical and services allied to medicine

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

Patients with neurological diseases under age 65 frequently do not receive adequate rehabilitation nor support at home as services are geared to over 65s

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

Depends on staffing in the community and educating and encouraging local services

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Strongly Agree

**b) Promote development of non-pharmacological interventions**

Agree

**c) Conduct multi-centre primary prevention studies**

Neutral

**d) Ensure better patient selection/stratification**

Strongly Agree

**e) Rethink approach to therapeutics**

Strongly Agree

**f) Support for high-risk projects**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Increase involvement of individuals in research

**Second Priority**

d) Ensure better patient selection/stratification

**Third Priority**

e) Rethink approach to therapeutics

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

It requires a person to person conversation explaining brain donation and the potential benefits to the family and our population as a whole - most patients agree to brain donation if it is explained clearly

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

Education and ongoing education/social activity Exercise

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Strongly Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

Strongly Agree

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Agree

**h) Develop more representative animal and cell-based models of disease**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Improve understanding of disease mechanisms

**Second Priority**

d) Develop an improved understanding of the genetic basis

**Third Priority**

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

d) The biological basis of behavioural and psychological symptoms

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

Perhaps - neurodegenerative disorders are lethal and many patients want to try something to see if it could slow or arrest the disease - there is a role for clinician-led trial

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Agree

**c) Develop new biomarkers**

Strongly Agree

**d) Consider regulatory approaches**

Agree

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

c) Providing an indicator of, and sensitivity to, disease progression

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

Strongly Agree

**b) Improve access to patient groups, samples and data**

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

**d) Develop a register of persons with cognitive impairment**

Strongly Agree

**e) Develop centres of excellence**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Improve data and sample collection

**Second Priority**

e) Develop centres of excellence

**Third Priority**

e) Develop centres of excellence

**Question 3: What can be done to facilitate increased sharing of data?**

Ensure subsequent papers acknowledge the generous donation and include the senior author on the paper

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

difficulties are surmountable

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

There is always the concern of 'dumbing-down' the other physicians and also the specialist becomes too removed from the real world of patients

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Agree

**b) Ensure greater engagement with regulators**

Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Agree

**f) Review and update legislation on treatment**

Neutral

**g) Review and update legislation on privacy and data disclosure**

Neutral

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Facilitate research in areas outside university and hospital sectors

**Second Priority**

e) Rethink patent lifetime and conduct public-private clinical trials

**Third Priority**

d) Encourage industry to adopt pre-competitive approach

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

Encourage researcher-led trials - less expensive and hypothesis-based

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Agree

**b) Encourage open-access sharing of data and materials**

Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Joint academic-industry funding models

**Second Priority**

a) Translational research needs to be promoted

**Third Priority**

e) Maintain capacity for 'bottom-up' innovative funding

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

As a busy neurologist I find it very difficult to get time to do or plan the research - there is need for more neurologist and also for research and teaching

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

It is frustrating to not have enough support or time to link the clinical phenotype, database, radiology and genetics with the molecular aspects etc -,this comes down to not recognizing we need to prospectively collect the clinical phenotype (video etc), radiology, and pathology of our patients. Resources are needed to do this and free up some time of individuals to drive a hard bargain

**UID**

2046

**Title**

Dr

**First Name**

Charlotte

**Surname**

Morgan

**Category of respondee**

Healthcare professional - General Practitioner

**Replying on behalf of organisation/company?**

No

**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**

Neutral

**e) Increase numbers of post-doctoral level researchers**

Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

b) Improve education and training of healthcare professionals

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

Carers

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Neutral

**b) Survey long-term care standards and provision across Europe**

Strongly Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Agree

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Rethink approaches to care

**Second Priority**

b) Survey long-term care standards and provision across Europe

**Third Priority**

c) Research into the needs of carers

**Question 3: How would you define "care"?**

Considering and responding to the physical and psychological needs of a person.

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

Look closely at the standard of the care being provided. Educate carers. Consider a standardised qualification for carers looking after older people and those who have NDD including written papers but observed practice. Can they communicate effectively? Can they see and respond to the needs of the client? Look at the numbers of carers. Consider incentives for becoming a carer. Look at a support network for carers. Increase respite places.

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Agree

**b) Promote development of non-pharmacological interventions**

Agree

**c) Conduct multi-centre primary prevention studies**

Neutral

**d) Ensure better patient selection/stratification**

Disagree

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Neutral

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Increase involvement of individuals in research

**Second Priority**

b) Promote development of non-pharmacological interventions

**Third Priority**

e) Rethink approach to therapeutics

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

Through education. Clinicians are not aware of trials, therefore the patients won't be.

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Strongly Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

Neutral

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Strongly Agree

**h) Develop more representative animal and cell-based models of disease**

Neutral

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Improve understanding of disease mechanisms

**Second Priority**

g) Establish pan-European population-based studies

**Third Priority**

a) Understand relationship between NDD and ageing

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

c) Mechanisms of neuronal death and dysfunction

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Agree

**c) Develop new biomarkers**

Strongly Agree

**d) Consider regulatory approaches**

Neutral

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

b) Linking to treatment responses

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

Agree

**b) Improve access to patient groups, samples and data**

Agree

**c) Improve data and sample collection**

Agree

**d) Develop a register of persons with cognitive impairment**

Neutral

**e) Develop centres of excellence**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Develop centres of excellence

**Second Priority**

b) Improve access to patient groups, samples and data

**Third Priority**

a) Improve access to, and sharing of, infrastructure and resources

**Question 3: What can be done to facilitate increased sharing of data?**

very difficult as confidentiality is the first priority. With patient's permission upload data/details to a central server similar to the 'nhs spine'

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Strongly Agree

**b) Ensure greater engagement with regulators**

Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Agree

**f) Review and update legislation on treatment**

Agree

**g) Review and update legislation on privacy and data disclosure**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

**Second Priority**  
**Third Priority**

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## **Funding and funding mechanisms**

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Translational research needs to be promoted**  
Agree
- b) **Encourage open-access sharing of data and materials**  
Agree
- c) **Joint academic-industry funding models**  
Agree
- d) **Simplify funding application systems**  
Agree
- e) **Maintain capacity for 'bottom-up' innovative funding**  
Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**  
**Second Priority**  
**Third Priority**

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## **Concluding questions**

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

UID

1515

Category of respondee

Healthcare professional - Psychiatrist

Country

Norway

## Education, training and collaboration

Question 1: Please indicate to what extent you endorse the following points

a) Improve dialogue between researchers and the wider population

Agree

b) Improve education and training of healthcare professionals

Agree

c) Increase numbers of neurodegenerative disease (NDD) researchers

Agree

d) Increase training for translational and clinician-scientists

Agree

e) Increase numbers of post-doctoral level researchers

Strongly Agree

Question 2: If you had to choose one priority from the points above what would it be?

e) Increase numbers of post-doctoral researchers

Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?

## Health and social care issues

Question 1: Please indicate to what extent you endorse the following points

a) Define the term "care"

Neutral

b) Survey long-term care standards and provision across Europe

Neutral

c) Research into the needs of carers

Disagree

d) Research into care approaches including end of life decision-making

Neutral

e) Rethink approaches to care

Agree

f) Understand and investigate influence of comorbidities

Agree

g) Conduct research into effects of nutrition and frailty

Neutral

h) Determine cost-effectiveness of healthcare pathways

Neutral

Question 2: Please rank the suggestions in order of priority

First Priority

d) Research end of life decision making

Second Priority

f) Understand and investigate influence of comorbidities on NDD

Third Priority

Question 3: How would you define "care"?

Question 4: Have you any (additional) suggestions as to how care systems should be revised?

Focus on how to stimulate personal continuity care, ie how the same professional carers can give service to the patient over long time.

Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?

## Prevention/treatment strategies and trials

Question 1: Please indicate to what extent you endorse the following points

a) Increase involvement of individuals in research

Agree

b) Promote development of non-pharmacological interventions

c) Conduct multi-centre primary prevention studies

Agree

**d) Ensure better patient selection/stratification**

Agree

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Conduct multi-centre primary prevention studies

**Second Priority**

b) Promote development of non-pharmacological interventions

**Third Priority**

d) Ensure better patient selection/stratification

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

## **Disease cause, mechanisms and models**

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Agree

**b) Improve understanding of disease stages**

Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Agree

**e) Determine the importance of genetic and environmental risk factors**

Neutral

**f) Focus research on rare hereditary forms of disease**

Neutral

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Neutral

**h) Develop more representative animal and cell-based models of disease**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

h) Develop more representative animal and cell-based models

**Second Priority**

e) Determine the importance of genetic and environmental risk factors

**Third Priority**

c) Improve understanding of disease mechanisms

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

b) Neuronal inflammation

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

## **Diagnosis, disease definitions and outcome measures**

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Strongly Agree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Disagree

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

b) Linking to treatment responses

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Improve access to, and sharing of, infrastructure and resources**  
Agree
- b) **Improve access to patient groups, samples and data**  
Agree
- c) **Improve data and sample collection**  
Agree
- d) **Develop a register of persons with cognitive impairment**  
Neutral
- e) **Develop centres of excellence**  
Neutral

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- c) Improve data and sample collection

**Second Priority**

- b) Improve access to patient groups, samples and data

**Third Priority**

- a) Improve access to, and sharing of, infrastructure and resources

**Question 3: What can be done to facilitate increased sharing of data?**

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Need for evidence-based policy**  
Strongly Agree
- b) **Ensure greater engagement with regulators**  
Strongly Disagree
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**  
Neutral
- d) **Encourage industry to adopt a pre-competitive approach to research**  
Agree
- e) **Rethink patent lifetime and conduct public-private clinical trials**  
Agree
- f) **Review and update legislation on treatment**  
Agree
- g) **Review and update legislation on privacy and data disclosure**  
Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- a) Need for evidence-based policy

**Second Priority**

- d) Encourage industry to adopt pre-competitive approach

**Third Priority**

- e) Rethink patent lifetime and conduct public-private clinical trials

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Translational research needs to be promoted**  
Neutral
- b) **Encourage open-access sharing of data and materials**  
Agree
- c) **Joint academic-industry funding models**  
Strongly Agree
- d) **Simplify funding application systems**  
Strongly Agree

**e) Maintain capacity for 'bottom-up' innovative funding**  
Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Maintain capacity for 'bottom-up' innovative funding

**Second Priority**

d) Simplify funding application systems

**Third Priority**

c) Joint academic-industry funding models

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## **Concluding questions**

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

UID

1666

**Category of respondee**

Healthcare professional - Geriatrician

**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?**

d) Increase training for translational and clinician-scientists

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

There is a need to acknowledge the overlap between neurodegenerative diseases and diseases which relate to them closely, like vascular cognitive impairment (and associated vascular diseases) and delirium, as well as the functional impact of neurodegenerative disease itself. There is also a need to see research and clinical practice in a lifecourse perspective, linking antenatal, postnatal, pediatric, adult and geriatric research and healthcare.

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Disagree

**b) Survey long-term care standards and provision across Europe**

Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Strongly Agree

**g) Conduct research into effects of nutrition and frailty**

Agree

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

f) Understand and investigate influence of comorbidities on NDD

**Second Priority**

d) Research end of life decision making

**Third Priority**

e) Rethink approaches to care

**Question 3: How would you define "care"?**

This is context dependent and I don't think one definition can incorporate all meanings (adjective and noun). I would define it as 'responsibility towards someone's needs'

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

Integrating assessments by health and social services. Ensuring regular review, including advance care planning. Systems to identify those at high risk eg of delirium, infection, rapid deterioration, to ensure plans in place about escalation of care, and identifying those at risk eg when admitted to hospital. Ensure a current summary of functional level included for those in residential care.

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

Ensure that a choice for care at home is informed by both advantages and disadvantages. Improve care provided at home (better pay and training for paid carers, and training and support for unpaid carers (relatives)). Improved professional support eg health visitors, community psychiatric nurses etc (funding constraints have meant these are often being reduced in the UK).

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Strongly Agree

**b) Promote development of non-pharmacological interventions**

Strongly Agree

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Disagree

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Conduct multi-centre primary prevention studies

**Second Priority**

a) Increase involvement of individuals in research

**Third Priority**

b) Promote development of non-pharmacological interventions

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

Ensure a discussion is had after diagnosis (and associated support) with every patient and their carer, to offer registration for a register which would allow contact for research (with no obligation to participate). Discuss annually? Should be initiated by main supervisor of clinical care (?psychiatrist, neurologist, geriatrician, CPN) but could be followed up by research nurse to provide additional information.

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

Role of controlling vascular risk factors or exercise on cognitive decline. Also an area for using targetted subgroups: target 'at risk' populations, eg due to family history, genetics, or vascular risk factors (eg diabetes, peripheral vascular disease, cardiovascular disease). Could look at impact of antenatal care on later life outcome (cohort study rather than trial, and very long time lag to results).

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Strongly Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

Disagree

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Agree

**h) Develop more representative animal and cell-based models of disease**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

b) Improve understanding of disease stages

**Second Priority**

a) Understand relationship between NDD and ageing

**Third Priority**

c) Improve understanding of disease mechanisms

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

d) The biological basis of behavioural and psychological symptoms

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

If animal models are not felt to be a useful surrogate for the clinical situation, the disease is very debilitating, and the treatment low risk.

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

a) Redefine and standardise disease definitions and diagnosis

Neutral

b) Redefine and harmonise clinical endpoints and outcomes

Agree

c) Develop new biomarkers

Agree

d) Consider regulatory approaches

Neutral

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

a) Improve access to, and sharing of, infrastructure and resources

Agree

b) Improve access to patient groups, samples and data

Agree

c) Improve data and sample collection

Strongly Agree

d) Develop a register of persons with cognitive impairment

Strongly Agree

e) Develop centres of excellence

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

d) Develop a register of persons with cognitive impairment

**Second Priority**

c) Improve data and sample collection

**Third Priority**

e) Develop centres of excellence

**Question 3: What can be done to facilitate increased sharing of data?**

Need a more open culture of data sharing between researchers. This is progressing, and more collaborative research is ongoing.

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

I'm in favour of open access data, but researchers who have invested time and money in collecting this should have a reasonable time period to perform the analyses predetermined, and should be acknowledged in related publications.

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

If these also concentrate clinical centres then access may be difficult for people in remote areas.

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

a) Need for evidence-based policy

Strongly Agree

b) Ensure greater engagement with regulators

Strongly Agree

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

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**

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**

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**

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**

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)**

Key to success will be encouraging communication between the disparate groups involved in this research (neurologists, geriatricians, psychiatrists, neuroradiologists, basic scientists, epidemiologists etc), both in the research and clinical environments.

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

Encouragement to organisations to increase inter-disciplinary working. Reduced rates at conferences to non-specialists?

**Question 3: Is there anything else you would like to tell us?**

**UID**

1715

**Category of respondee**

Healthcare professional - General Practitioner

**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**

Neutral

**e) Increase numbers of post-doctoral level researchers**

Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

b) Improve education and training of healthcare professionals

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Neutral

**b) Survey long-term care standards and provision across Europe**

Neutral

**c) Research into the needs of carers**

Agree

**d) Research into care approaches including end of life decision-making**

Neutral

**e) Rethink approaches to care**

Neutral

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Strongly Agree

**h) Determine cost-effectiveness of healthcare pathways**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

g) Conduct research into effects of nutrition and frailty

**Second Priority**

h) Determine cost-effectiveness of healthcare pathways

**Third Priority**

c) Research into the needs of carers

**Question 3: How would you define "care"?**

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Neutral

**b) Promote development of non-pharmacological interventions**

Agree

**c) Conduct multi-centre primary prevention studies**

Strongly Agree

**d) Ensure better patient selection/stratification**

Agree

**e) Rethink approach to therapeutics**

Agree

**f) Support for high-risk projects**

Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Conduct multi-centre primary prevention studies

**Second Priority**

e) Rethink approach to therapeutics

**Third Priority**

f) Support for high-risk projects

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

Homocysteine lowering; effects of B vitamins and other antioxidants

## **Disease cause, mechanisms and models**

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Agree

**b) Improve understanding of disease stages**

Neutral

**c) Improve understanding of disease mechanisms**

Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Agree

**e) Determine the importance of genetic and environmental risk factors**

Agree

**f) Focus research on rare hereditary forms of disease**

Disagree

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Agree

**h) Develop more representative animal and cell-based models of disease**

Neutral

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

e) Determine the importance of genetic and environmental risk factors

**Second Priority**

c) Improve understanding of disease mechanisms

**Third Priority**

a) Understand relationship between NDD and ageing

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

b) Neuronal inflammation

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

## **Diagnosis, disease definitions and outcome measures**

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Disagree

**b) Redefine and harmonise clinical endpoints and outcomes**

Neutral

**c) Develop new biomarkers**

Agree

**d) Consider regulatory approaches**

Neutral

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

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

Neutral

c) Improve data and sample collection

Neutral

d) Develop a register of persons with cognitive impairment

Agree

e) Develop centres of excellence

Neutral

**Question 2: Please rank the suggestions in order of priority**

First Priority

Second Priority

Third Priority

**Question 3: What can be done to facilitate increased sharing of data?**

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

a) Need for evidence-based policy

b) Ensure greater engagement with regulators

c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community

d) Encourage industry to adopt a pre-competitive approach to research

e) Rethink patent lifetime and conduct public-private clinical trials

f) Review and update legislation on treatment

g) Review and update legislation on privacy and data disclosure

**Question 2: Please rank the suggestions in order of priority**

First Priority

Second Priority

Third Priority

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

a) Translational research needs to be promoted

b) Encourage open-access sharing of data and materials

c) Joint academic-industry funding models

d) Simplify funding application systems

e) Maintain capacity for 'bottom-up' innovative funding

**Question 2: Please rank the suggestions in order of priority**

First Priority

Second Priority

Third Priority

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

UID

1963

**Category of respondee**

Healthcare professional - Neurologist

**Country**

Slovenia

## Education, training and collaboration

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve dialogue between researchers and the wider population**

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

**c) Increase numbers of neurodegenerative disease (NDD) researchers**

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Strongly Agree

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

c) Increase overall numbers of researchers

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Agree

**b) Survey long-term care standards and provision across Europe**

Strongly Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Agree

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Agree

**h) Determine cost-effectiveness of healthcare pathways**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

c) Research into the needs of carers

**Second Priority**

f) Understand and investigate influence of comorbidities on NDD

**Third Priority**

h) Determine cost-effectiveness of healthcare pathways

**Question 3: How would you define "care"?**

Care, in my mind, encompasses everything that an individual with dementia needs beyond what the family provides while with family and everything when taken care by other caregivers i.e. in institution.

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

Strongly believe that it should be centered around general practitioners as this improved the quality of life of patients, their families and reduced the cost without significantly the quality of care if done appropriately.

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

Dementia patients should get all and more help when at home as once they leave their homes everything is different for them plus care becomes more expensive.

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Increase involvement of individuals in research**  
Strongly Agree
- b) **Promote development of non-pharmacological interventions**  
Strongly Agree
- c) **Conduct multi-centre primary prevention studies**  
Strongly Agree
- d) **Ensure better patient selection/stratification**  
Strongly Agree
- e) **Rethink approach to therapeutics**  
Strongly Agree
- f) **Support for high-risk projects**  
Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- e) Rethink approach to therapeutics

**Second Priority**

- a) Increase involvement of individuals in research

**Third Priority**

- c) Conduct multi-centre primary prevention studies

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

Better education, marketing.

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

Though call. We need more basic reserch to get good clues about what to probe for.

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Understand relationship between neurodegenerative disease and ageing**  
Strongly Agree
- b) **Improve understanding of disease stages**  
Strongly Agree
- c) **Improve understanding of disease mechanisms**  
Strongly Agree
- d) **Develop an improved understanding of the genetic basis for NDD**  
Strongly Agree
- e) **Determine the importance of genetic and environmental risk factors**  
Strongly Agree
- f) **Focus research on rare hereditary forms of disease**  
Strongly Agree
- g) **Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**  
Strongly Agree
- h) **Develop more representative animal and cell-based models of disease**  
Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- c) Improve understanding of disease mechanisms

**Second Priority**

- a) Understand relationship between NDD and ageing

**Third Priority**

- e) Determine the importance of genetic and environmental risk factors

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

- c) Mechanisms of neuronal death and dysfunction

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

No way. I have been in the Alzheimer's and related disease field for over 15 years as a basic neuroscientist with several years of bench work and also as a cognitive neurologist seeing pateints. Cell models are great, they contributed a lot in the early 90s to learn about APP, abeta, etc....and still play an important role, but jumping from cells (i.e. non physiological amounts of abetadumped onto kidney cells?) straingth to humans I don't think this is scientifically sound. Moreover, even the best animal models are far away from real disease. Cell or animal models are good for testing very specific disease related questions and animal models are an important step in designing human research.

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Redefine and standardise disease definitions and diagnosis**  
Strongly Agree
- b) **Redefine and harmonise clinical endpoints and outcomes**  
Strongly Agree
- c) **Develop new biomarkers**  
Strongly Agree
- d) **Consider regulatory approaches**  
Strongly Agree

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

- a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Improve access to, and sharing of, infrastructure and resources**  
Strongly Agree
- b) **Improve access to patient groups, samples and data**  
Strongly Agree
- c) **Improve data and sample collection**  
Strongly Agree
- d) **Develop a register of persons with cognitive impairment**  
Strongly Agree
- e) **Develop centres of excellence**  
Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- a) Improve access to, and sharing of, infrastructure and resources

**Second Priority**

- b) Improve access to patient groups, samples and data

**Third Priority**

- c) Improve data and sample collection

**Question 3: What can be done to facilitate increased sharing of data?**

Change the mindset in Europe. In my example, when I returned back home with reasonable knowledge and publications in journals including Science and Neuron no one cared, even more, some tried to block my every attempt to continue research. And I know this happens in many places across Europe.

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

This needs good regulation and control.

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

No, we absolutely need them, but in Europe this will lead to fights as everyone will want to develop a Center of excellence.

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

- a) **Need for evidence-based policy**  
Strongly Agree
- b) **Ensure greater engagement with regulators**  
Strongly Agree
- c) **Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**  
Strongly Agree
- d) **Encourage industry to adopt a pre-competitive approach to research**  
Strongly Agree
- e) **Rethink patent lifetime and conduct public-private clinical trials**  
Strongly Agree
- f) **Review and update legislation on treatment**  
Strongly Agree
- g) **Review and update legislation on privacy and data disclosure**  
Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- a) Need for evidence-based policy

**Second Priority**

- c) Facilitate research in areas outside university and hospital sectors

**Third Priority**

- e) Rethink patent lifetime and conduct public-private clinical trials

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

New money.

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Strongly Agree

**b) Encourage open-access sharing of data and materials**

Agree

**c) Joint academic-industry funding models**

Agree

**d) Simplify funding application systems**

Strongly Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

- d) Simplify funding application systems

**Second Priority**

- a) Translational research needs to be promoted

**Third Priority**

- b) Encourage open-access sharing of data and materials

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

Maybe it could be achieved in the same way as companies breeding animal models and stem cells work in US?

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

Think nepotism and despotism are more typical of Europe than of the US and this is in our disadvantage, we should find ways to get rid of it.

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

**Question 3: Is there anything else you would like to tell us?**

UID

2145

Category of respondee

Healthcare professional - Neurologist

Country

Italy

## Education, training and collaboration

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve dialogue between researchers and the wider population**

Strongly Agree

**b) Improve education and training of healthcare professionals**

Strongly Agree

**c) Increase numbers of neurodegenerative disease (NDD) researchers**

Strongly Agree

**d) Increase training for translational and clinician-scientists**

Agree

**e) Increase numbers of post-doctoral level researchers**

Strongly Agree

**Question 2: If you had to choose one priority from the points above what would it be?**

b) Improve education and training of healthcare professionals

**Question 3: Are there any other specialist areas which you think need promoting or should be given greater emphasis?**

I think that use of neuropsychological tests in current clinical practice should be based on highest quality of normative population data.

## Health and social care issues

**Question 1: Please indicate to what extent you endorse the following points**

**a) Define the term "care"**

Agree

**b) Survey long-term care standards and provision across Europe**

Strongly Agree

**c) Research into the needs of carers**

Strongly Agree

**d) Research into care approaches including end of life decision-making**

Strongly Agree

**e) Rethink approaches to care**

Strongly Agree

**f) Understand and investigate influence of comorbidities**

Agree

**g) Conduct research into effects of nutrition and frailty**

Strongly Agree

**h) Determine cost-effectiveness of healthcare pathways**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

g) Conduct research into effects of nutrition and frailty

**Second Priority**

b) Survey long-term care standards and provision across Europe

**Third Priority**

h) Determine cost-effectiveness of healthcare pathways

**Question 3: How would you define "care"?**

The care term means the overall treatments (pharmacological and non -pharmacological) with which the patient and caregiver have treated.

**Question 4: Have you any (additional) suggestions as to how care systems should be revised?**

From the disease management point of view I think that social and health services should be considered together.

**Question 5: Provision of care at home has both advantages and disadvantages, how do you suggest we change the balance to promote the advantages?**

We must choose the treatments based on good evidences.

## Prevention/treatment strategies and trials

**Question 1: Please indicate to what extent you endorse the following points**

**a) Increase involvement of individuals in research**

Strongly Agree

**b) Promote development of non-pharmacological interventions**

Strongly Agree

**c) Conduct multi-centre primary prevention studies**

Agree

**d) Ensure better patient selection/stratification**

Strongly Agree

**e) Rethink approach to therapeutics**

Strongly Agree

**f) Support for high-risk projects**

Strongly Disagree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

f) Support for high-risk projects

**Second Priority**

d) Ensure better patient selection/stratification

**Third Priority**

a) Increase involvement of individuals in research

**Question 3: How can we encourage more people to take part in research and/or register to donate brain material?**

I think that an serious national project on biobank should be implemented in each european country.

**Question 4: If you think we are in the position to begin multi-centre primary prevention trials, what measures do you think should be trialled?**

For example the conversion from mild cognitive impairment to dementia. Or the conversion from normal cognitive health status to MCI.

## Disease cause, mechanisms and models

**Question 1: Please indicate to what extent you endorse the following points**

**a) Understand relationship between neurodegenerative disease and ageing**

Strongly Agree

**b) Improve understanding of disease stages**

Strongly Agree

**c) Improve understanding of disease mechanisms**

Strongly Agree

**d) Develop an improved understanding of the genetic basis for NDD**

Strongly Agree

**e) Determine the importance of genetic and environmental risk factors**

Strongly Agree

**f) Focus research on rare hereditary forms of disease**

Agree

**g) Establish pan-European population-based studies including year-on-year (longitudinal) studies in high risk groups**

Strongly Agree

**h) Develop more representative animal and cell-based models of disease**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Understand relationship between NDD and ageing

**Second Priority**

e) Determine the importance of genetic and environmental risk factors

**Third Priority**

b) Improve understanding of disease stages

**Question 3: In relation to disease mechanisms which of the following do you think it is most important to investigate?**

c) Mechanisms of neuronal death and dysfunction

**Question 4: Do you think there could be justification for progressing research from cell-based models straight to humans (i.e. missing out animal models)? If so please explain under what circumstances this could be acceptable**

I think that only in very particular conditions the animal models may be ignored: the results from cell-based models should be particularly positive and consistent.

## Diagnosis, disease definitions and outcome measures

**Question 1: Please indicate to what extent you endorse the following points**

**a) Redefine and standardise disease definitions and diagnosis**

Strongly Disagree

**b) Redefine and harmonise clinical endpoints and outcomes**

Strongly Agree

**c) Develop new biomarkers**

Strongly Agree

**d) Consider regulatory approaches**

Strongly Agree

**Question 2: Which of the following do you think is most important in terms of biomarkers?**

a) Linking to the mechanism of disease and functional endpoints

## Data, registries, repositories and centres

**Question 1: Please indicate to what extent you endorse the following points**

**a) Improve access to, and sharing of, infrastructure and resources**

Strongly Agree

**b) Improve access to patient groups, samples and data**

Strongly Agree

**c) Improve data and sample collection**

Strongly Agree

**d) Develop a register of persons with cognitive impairment**

Strongly Agree

**e) Develop centres of excellence**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Improve access to, and sharing of, infrastructure and resources

**Second Priority**

e) Develop centres of excellence

**Third Priority**

c) Improve data and sample collection

**Question 3: What can be done to facilitate increased sharing of data?**

I think that an multidisciplinary consortium should be created.

**Question 4: What are your views on making data open access? If you foresee difficulties, how can we overcome these?**

I think that an specific protocol should be performed.

**Question 5: Relating to point (e) do you see any risk(s) in developing centres of excellence?**

Yes, I think the the centres of excellence should be prevalently public.

## Policy, regulation and legislation

**Question 1: Please indicate to what extent you endorse the following points**

**a) Need for evidence-based policy**

Strongly Agree

**b) Ensure greater engagement with regulators**

Strongly Agree

**c) Facilitate research in areas outside the universities and hospitals in sectors such as care homes and within the wider community**

Strongly Agree

**d) Encourage industry to adopt a pre-competitive approach to research**

Strongly Agree

**e) Rethink patent lifetime and conduct public-private clinical trials**

Strongly Agree

**f) Review and update legislation on treatment**

Disagree

**g) Review and update legislation on privacy and data disclosure**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

a) Need for evidence-based policy

**Second Priority**

c) Facilitate research in areas outside university and hospital sectors

**Third Priority**

d) Encourage industry to adopt pre-competitive approach

**Question 3: Can you suggest any further policy or regulatory approaches that might encourage or promote the development of new treatments?**

I think that regulatory approaches should encourage and consider the use of valid surrogate end-point in all clinical trials.

## Funding and funding mechanisms

**Question 1: Please indicate to what extent you endorse the following points**

**a) Translational research needs to be promoted**

Agree

**b) Encourage open-access sharing of data and materials**

Strongly Agree

**c) Joint academic-industry funding models**

Strongly Agree

**d) Simplify funding application systems**

Strongly Agree

**e) Maintain capacity for 'bottom-up' innovative funding**

Strongly Agree

**Question 2: Please rank the suggestions in order of priority**

**First Priority**

b) Encourage open-access sharing of data and materials

**Second Priority**

a) Translational research needs to be promoted

**Third Priority**

b) Encourage open-access sharing of data and materials

**Question 3: Please expand on point (b) if you have any experience or suggestions for alternatives that may help us achieve this goal**

## Concluding questions

**Question 1: Are there strategies you think we have overlooked, if so please suggest below (up to three suggestions)**

I suggest a higher quality of basic research because only when there are solid evidences in this sector, they should be transferred in the clinical research.

**Question 2: Do you have any comments on how to implement the above suggestion(s)?**

I think that a public health perspective should be conserved in this specific area of research because the risk of a disease mongering situation may be always present.

**Question 3: Is there anything else you would like to tell us?**

I think that a major coordination of all european and national projects on neurodegenerative diseases is urgently necessary.