

## **APPG on Dementia: Dementia Research Inquiry – Oral Evidence Session**

### **Session 1: Why is now the time to turn the tide on dementia research?**

**Date:** Wednesday 14<sup>th</sup> April 2021

**APPG Officers in attendance:** Debbie Abrahams MP; Baroness Sally Greengross.

#### **Witnesses:**

- Jane Ward, Alzheimer’s Society Research Network Volunteer
- Prof Bart De Strooper, Director of UK Dementia Research Institute
- Prof Martin Rossor, National Dementia Director at National Institute for Health Research
- David Thomas, Head of Policy at Alzheimer’s Research UK

#### **Background**

At the most recent AGM, the Group agreed to conduct an inquiry into the current state of dementia research in the UK. The inquiry will consider how the pandemic has affected the research field, with particular focus on the impact it has had on early career researchers.

The inquiry will also consider what support the Government can give to the sector – including the realisation of their commitment to double dementia research funding to £166m per year<sup>1</sup> – and how this money can be best spent to ensure that the UK is a world leader in dementia research.

This was the first of four sessions, which looked gain an understanding current state of dementia research in the UK, how we compare internationally, what could be achieved with the ‘Moonshot’ and how the pandemic has affected dementia research in the UK.

#### **Executive Meeting Summary**

- All the witnesses in attendance described the UK as being on a good footing for dementia research but there was an agreement that we now sit at a turning point, particularly with the effects covid-19 has had on the research community.
- Covid-19 has meant that much research has had to be paused or halted together, causing real issues for researchers’ career pathways. The pandemic has also caused significant financial impacts on medical research charities, including Alzheimer’s Research UK.
- The ‘Moonshot’, as a policy, was welcomed by all attendees and all agreed that it would make a huge difference to the landscape of dementia research in the UK.
- It was felt by all attendees that the pandemic reinforced the need for the ‘Moonshot’ and increase the funding. The cost of inaction on this could set back what’s been achieved in the last 10 years.
- More needs to be done to encourage people to take part in research and far too often research is seen as something that is done to people, instead of something that can be done to support people living better lives. There was agreement that being involved in research can give a sense of empowerment, particularly to people living with dementia and their carers.

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<sup>1</sup>Conservatives. The Conservative and Unionist Party Manifesto 2019. [https://assets-global.website-files.com/5da42e2cae7ebd3f8bde353c/5dda924905da587992a064ba\\_Conservative%202019%20Manifesto.pdf](https://assets-global.website-files.com/5da42e2cae7ebd3f8bde353c/5dda924905da587992a064ba_Conservative%202019%20Manifesto.pdf)

## Full Meeting Summary

When asked to describe what drove her to become involved in dementia research, **Jane** shared her experience as a carer for her mother, who lived with dementia. **Jane** has involved herself in dementia research in several ways over the past 8 years, both before and after her mother's death. She spoke of the empowerment she felt when volunteering to support research and said that her other research volunteers also felt this. **Jane** said that as her mother's condition worsened and whilst she lost some skills, she was always able to be an expert on her own needs and how dementia was affecting her, and this helped her mother.

**Bart, Martin, and David** were each asked how they would describe the current state of dementia research in the UK. There was agreement that the UK is on a good footing and over the past decade has grown to become one of the most desirable places to come and work in the field in Europe and probably the world. However, there was a risk that this advantage would fall away without continued investment.

### Comparing the UK internationally

**Bart and Martin** were also asked how they thought the UK compared internationally in the field. Both agreed that the UK compares favourably, and only matched by perhaps the US. **Bart** said that whilst more funding was given in America, in the UK this funding is often a lot more targeted and often a lot more effective. It was agreed that the UK dementia research field was particularly strong in the research areas of Lewy bodies and Parkinson's dementia.

**Bart** pointed out that the German equivalent of the UK DRI's budget is nearly 4x that of the UK. **Martin** said that one of the areas where we do not compare internationally well is embedding research into our health services. When asked by the chair whether this was a cultural or capacity issue **Martin** replied that it was both. There is a culture of research being seen as something that is done to people, so patients are often protected by clinicians. There needs to be a cultural change in research and NHS, so the patients are informed and feel they have a choice to take part in research. **Bart** added to this and said that one of the UKDRI's aims is to integrate research with clinicians and it has been underestimated how hard it would be to bring these two together.

### Should the 'Moonshot' be a priority?

**David** was asked to give a brief overview of what the 'Dementia Moonshot' is and why it should be a priority for the Government. **David** said that the 'Moonshot' is a commitment in Conservative 2019 general election manifesto which promised to seek to 'find a cure' for dementia. The Government promised within this Parliament that they would double Government investment in dementia research from £83m a year to £166m for each year over the next decade. **David** said that he believed that this would help to build on the momentum there had already been over the last ten years, but the commitment still hasn't been realised. It is understandable why – a lot of attention has gone towards Covid-19 but as we're entering a new phase in the pandemic, Alzheimer's Research UK is making the case that that is more urgent now, not less, because of the effect that the pandemic has had on people with dementia.

**Debbie Abrahams MP** noted that Covid-19 has been shown to affect the nervous system and may be bringing forward symptoms of dementia. **David** added that whilst the Government made commitments to R&D spending, there had been no 'Moonshot' funding in the most recent Budget.

**Jane** was asked why, given her experience as a research volunteer and a carer of someone with dementia, she felt that dementia research should be treated as a priority by Government. Jane said that we have 850,000 people in UK with dementia and even more with mild cognitive impairment that may or may not develop into dementia. Jane also noted that there were about 100, maybe 200 forms of dementia. **Jane** said that despite how widespread dementia is we just don't know enough about it, and issues such as the sporting brain injuries need to be investigated.

**Jane** also said that 1 in 4 people dying with COVID have had dementia and those who have been isolated during COVID may have ordinarily provided care to family members with dementia. When her mum was ill five years ago, she went out less than in the lockdown brought on by the Covid-19 pandemic and felt incredibly isolated at home.

**Martin and Bart** were asked whether dementia was being appropriately funded, given that it's the UK biggest killer. **Martin and Bart** said it's important to make a comparison with other conditions. Dementia and cancer are both disorders from the body. He added that the number of people with dementia and the number of people with cancer worldwide were similar – approximately 56 million with cancer and 48 million with dementia. Currently funding for cancer in the UK is £270 million and funding for dementia is just £83 million. Even with the 'Moonshot' investment of £80m there would still be a large gap in research funding for the two conditions.

**Bart** said that the UKDRI had suffered tremendously from COVID –with the budget severely affected – and hoped that there's room to invest in basic research as part of any 'Moonshot'. He said he felt the UKDRI is the UK's rocket, and they just need the fuel.

When asked what the cost of inaction would be, **Martin** said that it would "make covid-19 look like a play in the park" and that dementia was not just something that happened in people's lives but was something that had a deep impact on people's lives and the economy. He added that dementia research funding is less than a sixth of what dementia costs the country.

**David** added that there were treatments available for cancer that will slow it and that we don't have that for dementia, but the impact it has is just going to affect more and more people.

**Bart** added that there were currently around 2,905 clinical trials for cancer in the UK, and only about 200 for dementia. The dementia research field sometimes gets criticism for not getting success, but there aren't enough trials. **Debbie Abrahams MP** added that many researchers will change the focus of their research if people don't think there's commitment to the field.

When asked what this additional funding could mean for them, **Martin** said that getting more young researchers is vital and, it's important we empower people to become involved in research. **Bart** said that for the UKDRI, this additional funding is existential and added that it's very difficult to break walls in silos in this research area without funding.

**David** added that a priority should be finding people with dementia but no symptoms to become involved in research. ARUK have recently launched their EDEN programme, which looks into the early detection of neuro-deterioration.

#### The effects of the pandemic.

**Baroness Greengross** asked how the pandemic was affecting dementia research organisations. **David** said that ARUK have been heavily impacted by the pandemic and the Association of Medical Research Charities estimated that its members have lost over £310m. He added that therefore

‘Moonshot’ is more urgent, not less urgent. He felt that funding will bounce back in 5 years, but there’s damage that sets us back in the meantime which is very concerning.

**Bart** said that the UKDRI was informed they could not raise the funding that they had promised last year. This has led to a postponement in research and a freeze on recruitment.

**Martin** said that clinical research hasn’t suffered as much as basic laboratory research. He added that some of the stories he had heard are including PhD researchers having to pack up and go home, nullifying 6 months of research. Looking into the future **Martin** is concerned at the affects of the pandemic on cognition.

**Jane** said that there were 350-400 active members of the network and they spend much of their time looking at applications for research, this helps Alzheimer’s Society decide what the most useful research for funding is This part of the process has been stopped since COVID and she is quite worried that members may not be active after the pandemic. **Jane** also added that many of the monitoring projects she had been working on had been delayed, including lab work, and that being able to chat to researchers – something that motivates them – has stopped. She also said that a young researcher also mentioned not getting the same idea sharing that she would benefit from in the laboratory. She added that some people with dementia have been unable to support or volunteer in ways that they might have previously as they have had difficulties navigating video calling technology.

#### Looking forward

**Debbie Abrahams MP** asked, outside of additional funding, what steps would the witnesses like to see Government take. **David** said that the response to COVID and vaccine rollout offers a particularly useful lesson that leadership is at least as important as investment. Government has a significant role in bringing together stakeholders and directing them towards common aims.. **Bart** agreed with David and added that we need to get away from fatalism in dementia research.

**Martin** said that leadership is critically important and that this year’s presidency of G7 is ideal time to look at what’s happened over the last 7 years in dementia care and research.

**Jane** added that there has been a huge amount of publicity on research for COVID, but mostly around the vaccine and that mostly people will think that research is sticking needles in people. She said that we need people to get involved in research and it should feel empowering, it’s not all about doing something to you. She finally added that when she talks about how you feel isolated as carers, for the first time since she started 8 years ago, people get what they mean about not going out for a month. She added that this understanding gives a great opportunity for dementia research.

**Debbie Abrahams MP** and **Baroness Sally Greenross** closed the session by thanking the witnesses for their contribution. **Debbie Abrahams MP** reminded the group that the next evidence session would take place on Thursday 29<sup>th</sup> April and would hear evidence from:

- **Fiona Carragher**, Director of Research and Influencing at Alzheimer’s Society.
- **Prof Dame Louise Robinson**, Professor of Primary Care and Ageing at Newcastle University.
- **Prof David Sharp**, Centre Director of UK DRI Care Research & Technology.
- **Prof John O’Brien**, Professor of Old Age Psychiatry at University of Cambridge.

The Group had also received several requests to open future sessions up publicly and so the next, and proceeding sessions, would be broadcast ‘webinar style’, enabling members of the public to watch live.