

Briefing on APPG on Dementia Report: Fuelling the Moonshot

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This briefing includes the following:

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1. Background to the report

The All-Party Parliamentary Group on Dementia is a cross-party group of Parliamentarians co-chaired by Debbie Abrahams MP and Baroness Sally Greengross. It aims to influence legislation and policy-making in order to improve the lives of people with dementia and their carers.

At the 2019 General Election, the Conservative Party made a commitment in their manifesto to bring forward a 'Dementia Moonshot' and "double dementia research funding over the next decade". This would increase Government funding for dementia research from £83m a year to £166m a year – resulting in an extra £800m for dementia research over the next 10 years.¹

As the Government is yet to realise this commitment or bring forward a timetable for when this extra funding might be expected, the APPG on Dementia decided to hold an inquiry into the current state of dementia research in the UK and investigate how this funding could be best used to support the field.

The APPG took written evidence from over 35 individuals and organisations and [held four oral evidence sessions](#), where they questioned 16 different witnesses. The APPG took evidence from world leading academics, research organisations, charitable funders, participants in research and people affected by dementia to better understand the issues.

2. Summary of recommendations

The report's central recommendation is that **the Government should bring forward the Dementia Moonshot funding as soon as possible**. However, the APPG also developed several further recommendations on what this extra funding could be used for and how the field could be better supported. The report also recommends that:

- Moonshot funding should be directed towards development of novel methods for early diagnosis, such as blood and other biomarkers for different types of dementia.
- Appropriate funding for the UK Dementia Research Institute should be confirmed for the next 10 years.
- Building on Alzheimer's Society's Centres of Excellence model, 3 new centres should be established which focus on some of the biggest challenges in dementia.
- The Moonshot should be used to establish a specific fund of £40m to support both clinical and preclinical postdoctoral research positions and talent retention in dementia research.

¹ Conservative Party Manifesto (2019) <https://www.conservatives.com/our-plan>

- The Government develops a Longitude Prize for dementia, which would support the development of novel technologies.
- The Government works with Join Dementia Research and NHS authorities to move JDR to an opt out model, with all newly diagnosed patients receiving a letter within 3 months of their diagnosis with information on how they can take part in research and the option to leave the database. They should also work to address data gaps by integrating JDR with electronic patient records.
- The newly-created Office for Health Promotion launches public information campaigns to explain how the public can take steps to reduce their dementia risk

3. Current state of dementia research in the UK

The APPG's inquiry sought to understand the current state of dementia research in the UK, with particular interest in the impact the pandemic has had on the field.

Dementia research and the economy

Between 2010 and 2018, government funding for dementia research increased from £28.2m to £82.5m. Despite this welcome increase, the report finds that dementia research remains relatively underfunded when compared to other conditions. For example, government research funding for cancer is almost 3 times higher than that for dementia – despite dementia the UK's leading cause of death.²

Government spending on research can also act as a catalyst to unlock further private funding. A study conducted by Oxford Economics in September 2020 found that each £1 of public research and development funding stimulates between £1.96 and £2.34 of private investment over the next 15 years.³

On this basis, an extra 'Moonshot' investment of £800m over the next decade, as promised by government, could unlock additional private investment of £1.6bn – £1.8bn.

Impacts of the pandemic on dementia research

Throughout the pandemic, many laboratories have had to be closed and/or have had their research suspended. The inability to access labs has affected many projects and has heavily impacted on research productivity.

The Group heard how preparations for research, including the development of cell structures and waiting for animals to reach the appropriate levels of maturity for testing, can take many months. The sudden impact of the pandemic has unfortunately put many of these investigations on indefinite hold.

The pandemic has had a devastating effect on the financial landscape of dementia research. Medical research charities, who fund 51% of all medical research in the UK, have seen their ability to fundraise drastically reduced.⁴

A survey from Alzheimer's Society, conducted in April 2021, found that 85% of researchers reported that the pandemic has led to fewer funding opportunities being available to them.⁵

² Alzheimer's Research UK (2019). Deaths due to dementia. [Online] Available at <https://www.dementiastatistics.org/statistics/deaths-due-to-dementia/>

³ Department of Business Energy & Industrial Strategy (2021). The relationship between public and private R&D funding. [Online] Available at [Research and development: relationship between public and private funding - GOV.UK \(www.gov.uk\)](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/94482/research-and-development-relationship-between-public-and-private-funding-GOV.UK.pdf)

⁴ Association of Medical Research Charities (2020). Covid-19 impacts on medical research charities. [Online] Available at <https://www.amrc.org.uk/Covid-19-the-risk-to-amrc-charities>

⁵ [Alzheimer's Society 2021 Survey into funding opportunities for researchers post pandemic](https://www.alzheimersociety.org.uk/2021/04/21/alzheimers-society-2021-survey-into-funding-opportunities-for-researchers-post-pandemic)

4. Areas of research

To develop recommendations and better understand the state of dementia research in the UK, the APPG sought to investigate several fields of research within the dementia research sector. These were:

Prevention research: The group heard in evidence how there is already a good scientific understanding of some of risk factors that can contribute to people developing dementia, including the 12 modifiable risk factors to reduce dementia risk as set out in a 2020 Lancet report.⁶

Despite this scientific understanding, there is generally little understanding amongst the public of how changes to their behaviour could reduce their risk of developing dementia. Alzheimer's Research UK's 'Dementia Attitudes Monitor' from 2018 showed that just 34% of people thought they could reduce their risk of developing dementia.⁷

The Group also took evidence from former England rugby player, Ben Kay. Ben discussed his participation in the PREVENT programme, a research initiative which follows healthy people throughout mid-life as well as some elite sportspeople in contact sports to monitor changes in their brain and identify the very earliest signs of dementia.

Biomedical research: Respondents to the inquiry expressed concerns that clinical trials can present many practical problems for the researchers running them. Respondents said that trials were difficult to fund – making the case for the Government's Dementia Moonshot even more important. The APPG heard how investment across the entire research pathway is imperative if research breakthroughs are to reach patients. By attracting more late-stage clinical trials, UK patients will have the best chance to get early access to potentially lifechanging treatments.

The APPG heard that there are many great centres in the UK carrying out important biomedical research, including the UK Dementia Research Institute. The UKDRI was highlighted in evidence as being a particular strength in the UK's research infrastructure and the APPG recommends that it should continued to be supported.

Early detection and diagnosis: The APPG took repeated evidence which highlighted that the current diagnostic methods in use for dementia are often costly and not suitable for use on a large-scale, or geographically inaccessible to much of the UK population. It was recommended that the research sector, private industry, and funders of research must come together to develop a more cost-effective approach to detecting the signs of diseases that cause dementia.

The APPG also heard how clinical translational research in this field, which investigates how discoveries generated in the laboratory or pre-clinical studies can be best applied, would lead to a greater understanding of the causes of dementia, and thus lead to earlier detection.

Care research and technology: The report finds that there are few services or approaches to care that are based on tested evidence. The Wellbeing and Health for People Living with Dementia (WHELD) project, funded by the National Institute for Health Research, starkly demonstrated this lack of evidence-based care. In a review of 170 training manuals for person-centred care in dementia, researchers found that just four provided evidence that methods had worked when tested in a research setting.⁸

The report recognises the work of the Centres of Excellence for dementia research at universities across the UK, and recommends these models should be replicated further.

⁶ [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

⁷ <https://www.alzheimersresearchuk.org/half-of-uk-adults-cant-identify-single-key-risk-factor-for-dementia/>

⁸ National Institute for Health Research (2020). WHELD Programme. [Online] Available at <https://evidence.nihr.ac.uk/alert/wheld-dementia-care-homes-person-centred-care>.

5. Supporting Early Career Researchers and promoting participation

During the inquiry the APPG also sought to understand how the dementia research workforce could be supported, and how participation in dementia research could be encouraged.

Early Career Researchers

The report finds that Early Career Researchers (ECR) within the field have been particularly affected by the pandemic, and that their careers as a whole have been impacted by other long-standing issues.

The report finds that the pandemic has had a serious impact on their careers and research, with many being locked out of labs for months due to lockdowns, or funding for their research ending early. The pandemic has also meant that many haven't been able to meet in person with other researchers to share expertise. Additionally, researchers have been unable to receive the full support and supervision from which they would usually benefit.

Many in research fellowships, which typically last 3 years, have lost up to 12 months' work through the pandemic. The report finds that there is fear among researchers that when they apply for funding for the next stage of their career. Many are concerned that lost time and experience means they will not be looked on as favourably as others who may be further along in their career, or whose work may not have been impacted as significantly by the pandemic..

A severe lack of funding opportunities often means researchers in the earlier stages of their career are unable to continue in the field.

Participation in research

The report details how people affected by dementia shared a sense of empowerment by being involved in research.

Due to the universality of healthcare through the NHS, the UK is better placed to drive participation in research than many other countries. However, the report finds that patients are often not aware of the opportunities to take part in research projects. A routine offer of research participation is not standard for people living with dementia in much of the NHS, and clinicians often do not have the time, nor incentive, to invite people to contribute.

The report highlights the Join Dementia Research (JDR) service, developed by the National Institute for Health Research and in which Alzheimer's Society, and Alzheimer's Research UK are partners. The service allows people to register their interest in participating in dementia research and be matched to suitable studies.

The report recommends that NIHR, Government, and the NHS should work together to drive up participation in dementia research by making JDR an opt out service for new dementia patients.
