

Fuelling the Moonshot: Unleashing the UK's potential through dementia research



All-Party
Parliamentary Group
on Dementia

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Contents

Foreword	5	Participation	27
Executive summary	6	Participation: Recommendation	29
Recommendations	6	Care Research and Technology	30
Introduction	8	Case Study: Alzheimer’s Society Centres of Excellence	31
About dementia	9	Care research and technology: Recommendation	32
The ‘Dementia Moonshot’ commitment	9	Conclusion	33
Dementia research in the UK	10	Appendix	35
Funding	11	Methodology	36
Comparisons with other conditions	11	References	38
Dementia research and the economy	12		
Recommendation: Dementia Moonshot funding	12		
Impact of Covid-19 on Dementia Research	13		
Delays to trials	14		
Charitable funding decimated	14		
Workforce and Early Career Researchers	15		
Workforce and Early Career Researchers: Recommendation	17		
Early Detection and Diagnosis	18		
Early detection and diagnosis: Recommendation	20		
Prevention	21		
Prevention: Recommendation	22		
Case Study: Prevention within sport	23		
Biomedical Research	24		
Biomedical: Recommendation	26		



Debbie Abrahams MP
Co-chair of the APPG
on Dementia



**Baroness Sally
Greengross OBE**
Co-chair of the
APPG on Dementia

Foreword

Dementia is the biggest non-communicable health challenge facing the world today, yet dementia research in the UK has been historically under-funded; with just 31p spent on dementia research for every £1 spent on cancer research.

Research can completely revolutionise how people with dementia are diagnosed, supported, cared for, and treated. A dementia diagnosis should not prevent a person being able to live a happy and fulfilling life, and good quality research is one of the most important tools available to us to ensure this is possible.

Our aim for this inquiry was to hear first-hand from people affected by dementia, researchers, charities, research organisations, and research participants, to understand the major issues currently affecting the sector and where the opportunities are to ensure the UK can cement its place as a world leader in dementia research.

The Covid-19 pandemic has touched all our lives in one way or another, but people with dementia and their loved ones have been among the hardest hit by the effects of the pandemic, and with around a quarter of all UK deaths caused by the virus being people with dementia.

Whilst we must now work to support those with dementia and their loved ones to recover from the disastrous effects of the pandemic, we must equally ensure that those who will develop dementia in the future will have the support they will need by investing in research today. Only through research can we ensure the best treatments, means of living well, and any future cures are available for the increasing numbers of people we are expecting to develop dementia in the years and decades ahead.

Despite the well-documented obstacles, the pandemic has also demonstrated the pace at which we can tackle major health challenges with the right leadership and targeted investment. The UK's life sciences sector has led the world in vaccine development and

genomic sequencing. It can do the same in dementia research, both biomedical and care research. For people affected by dementia, care and biomedical research are two sides of the same coin and it would be a false economy to focus on one over the other.

The Government's goal of elevating translational research in dementia, as set out in the recent Life Sciences Vision, is to be welcomed, but it will not be successful unless the dementia knowledge gap is filled, through sustained funding of discovery science.

We write this report appreciating that the Government has already shown leadership in this area, with funding for dementia research increasing significantly over recent years. And we commend the Conservative Party for committing to doubling dementia research funding again in its 2019 general election manifesto. This report has been drafted in anticipation of this commitment being fulfilled and seeks to set a strategy for how that extra funding can be best directed, to truly unleash the potential of the sector, while also driving innovation and growth across the entirety of the UK.

With long-awaited social care reform promised by the end of 2021, the growing number of people in the UK and worldwide projected to develop dementia, and the research momentum we have seen in recent years, it is a promising period for dementia research.

Dementia research can be a great UK success story, that has the potential to address a growing global challenge while also increasing skills and economic growth across all parts of the UK.



Debbie Abrahams MP
Co-chair of the APPG on Dementia



Baroness Sally Greengross OBE
Co-chair of the APPG on Dementia

Executive summary

The UK has seen increased investment for dementia research over the past decade. However, to truly revolutionise how people with dementia are diagnosed, treated medically, supported, and cared for, we cannot stop there. We must continue to build on this past success.

This report details the findings of the Group's inquiry into dementia research and what role the Government's commitment to funding a 'Dementia Moonshot' can make. During the inquiry the Group heard from a wide range of stakeholders to better understand the issues presently faced by the sector and where there are opportunities to cement the UK's status in the field of dementia research.

Undoubtedly, the pandemic has been immensely challenging for people affected by dementia, who have been worst hit by Covid-19. Equally, researchers have struggled both with their work being disrupted, and with securing financial backing for future projects; 85% of researchers reporting that the pandemic has reduced the number of funding opportunities available to them.

However, the pandemic has also created momentum in science and technology, which is the ideal springboard for the UK dementia research field to become the best in the world. This will help to ensure that people with

dementia are supported both now and in the future, offering the potential for earlier and more accurate diagnosis, and to develop much-needed treatments and cures for dementia, too.

Investing in dementia research creates huge economic opportunities. One study, conducted by Oxford Economics in September 2020, found that every £1 of public research and development spending stimulates between £1.96 and £2.34 of private investment.¹ On this basis, the Government's promise to provide Moonshot investment of £800m over the next decade could encourage private investment of between £1.6-1.8bn.

Recommendations

This report's central recommendation is for the Government to deliver on its manifesto commitment and fund the Dementia Moonshot as soon as possible, working with stakeholders to establish a timetable for this funding to be brought forward.



Providing this promised funding will be crucial to the Government's aims to level up the UK and make it a science superpower, as well as to the retention of the best and brightest researchers, including early career researchers.

Accompanying this central call to the Government, the report also makes several recommendations. These are:

1



That Moonshot funding is directed towards development of novel methods for early diagnosis, such as blood and other biomarkers for different types of dementia. Relevant systems must also be prepared to roll out these tests for wide use when validated.

2



Entrench the UK's global leadership in biomedical and translational dementia research by confirming appropriate funding for the UK Dementia Research Institute for the next 10 years.

3



Building on the success of the multidisciplinary approach of the Alzheimer's Society's Centres of Excellence model, further expanding it by introducing 3 new centres that will focus on some of the biggest challenges in dementia research that can have the biggest impact on the lives of people affected by dementia. This could include translation and the implementation of research.

4



For the Government to use the Moonshot to establish a specific fund of £40m to support both clinical and preclinical postdoctoral research positions and talent retention in dementia research.

5



For the Government to develop a Longitude Prize for dementia, which would support the development of novel technologies and help to ensure that the UK is at the forefront of developing technology for people with dementia and their carers.

6



The Government should work with Join Dementia Research and NHS authorities to maximise the success of JDR by:

- a) moving JDR to an opt out model. All newly diagnosed patients should receive a letter from the NHS within 3 months of their diagnosis providing information about how they can take part in dementia research and the option to leave the database if they wish.
- b) addressing data gaps by integrating JDR with electronic patient records. This would build on infrastructure developed by Dementia Platforms UK and Health Data Research UK to harmonise data across trial cohorts and link research data with clinical data. It would act as a mechanism to collect long term data on participants and track patient outcomes.

7



For the newly-created Office for Health Promotion to launch public information campaigns to explain how the public can take steps to reduce their dementia risk, and to generally increase people's understanding of dementia.

Introduction

About dementia

850,000 people in the UK are currently living with dementia, with that number set to rise to 1.3 million by 2030.²

Dementia describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. It is caused when the brain is damaged by diseases such as Alzheimer's disease. Dementia is progressive, which means the symptoms will gradually get worse. With 50 million people with dementia worldwide, dementia is also a global challenge. By 2030, the number of people living with dementia around the globe is set to rise to 82 million people.³

Every year dementia kills almost as many people in the UK as Covid-19 did in 2020.^{4,5} Prior to the Covid-19 pandemic, dementia was the leading cause of death in the UK; with the pandemic abating in the Spring of 2021, dementia has again regained this position.⁶ There are currently no significant pharmacological treatments available in the UK that can treat or cure the diseases that cause most forms of dementia.

The 'Dementia Moonshot' commitment

Over the past decade, consecutive governments have taken action to improve the lives of people with dementia, for example through the Prime Minister's Challenge on Dementia, first instigated by Prime Minister David Cameron in 2012.⁷

The Conservative Party's 2019 election manifesto sought to build on this progress by making a commitment to "save millions of people, and their families, from suffering the agony of a slow decline due to dementia." The party promised that it would "make finding a cure one of our Government's biggest collective priorities – one of the 'grand challenges' that will define our future...**This will include doubling research funding into dementia** and speeding up trials for new treatments".⁸

The party committed to invest "**more than £1.6 billion [...] into research over the next decade to find a cure for dementia under a Conservative majority government,**" which would provide the "**largest boost to dementia research ever in the UK, [would] double current funding levels, [and would set] Britain's finest scientists to work on a 'Dementia Moonshot'**".⁹

The 'Moonshot' promise complements the Government's aim to make the UK a "science superpower", and to use increased research and development funding to deliver economic growth across the UK as part of their aims to 'level up' regions.

The APPG on Dementia warmly welcomes this commitment to additional funding and believes that it is an important step to ensuring that the UK can cement itself as a world leader in dementia research. However, at the time of writing the Government has not yet brought forward this promised funding, nor has the Government set out a timetable for when the commitment will be met.¹⁰

Dementia research in the UK

Over the past decade, the UK has established a strong foothold in the field of dementia research. The UK Government has demonstrated its commitment to the field by using its presidency of the G8 in 2013 to promote the issue globally, implementing domestic policy commitments, such as the Prime Minister's Challenge on Dementia, and increasing funding for research.

These steps have now positioned the UK as one of the world's best places to undertake dementia research. The establishment of the UK Dementia Research Institute (jointly funded by Alzheimer's Society, Alzheimer's Research UK, and the Medical Research Council), the *Join Dementia Research* register, and infrastructure such as the Dementia Imaging Network, have all contributed to making the UK a particularly attractive place to conduct research for leading researchers from across the globe.

Funding

Between 2010 and 2018, government funding for dementia research increased from £28.2m to £82.5m.¹¹ This increase was welcomed by the Group and the wider research community. However, given dementia's position as the leading cause of death in the UK, and cancer research attracting almost three times as much funding, it is clear that further increases are necessary.¹²

The Group echoes the concerns of the National Institute for Health Research (NIHR) and UK Research and Innovation (UKRI) about the reduced budget for overseas development, from 0.7% of GDP to 0.5% of Gross National Income (GNI) due to the impacts this will have on UK research capability.¹³ The Official Development Assistance (ODA) does not just fund services in developing countries, but also funds research that is delivered in the UK for the benefit of less economically developed countries.

ODA funding supports the work of the NIHR and UKRI, two of the UK's most prominent funders of health research, with each funding £250m¹⁴ and £7.5bn¹⁵ worth of support for research projects and infrastructure per year, respectively.

In March 2021, UKRI expressed concerns that this funding cut would impact their work and *"would affect every UKRI Council... and will have whole-system impacts in the UK and overseas" and would leave them with a "£120m gap between allocations and commitments."*

This is concerning. Whilst the Government is rightly promoting the importance of investment in research and development, it is implementing a policy which could have the reverse impact. The Government should be providing more support to organisations such as UKRI and NIHR – not less.

By introducing the Dementia Moonshot funding now and working closely with stakeholders to put in place a timetable for this support, this disruption to research can be managed.

Comparisons with other conditions

In the oral evidence sessions, the Group heard from several witnesses who said that when compared to funding for research in other conditions, investment in dementia research is low. For example, government funding for cancer research sits at £269m a year¹⁶, compared to just £82.5m¹⁷ a year for dementia; this equates to just 31p for dementia research for every £1 spent on cancer research. Given dementia's position as the UK's leading cause of death since 2015¹⁸, government dementia research funding is disproportionately low.

This disparity in funding support is particularly acute in research capacity and the levels of clinical research taking place. While there are more than 20,000 researchers working in cancer research in the UK, there are just over 6,000 working on dementia.¹⁹ Between 2004 and 2020 in the UK there have been over 13 times more cancer clinical trials compared to dementia trials.²⁰

Without the appropriate funding, researchers are driven to other fields of research, taking with them years of experience and vital knowledge that could be used to improve the lives of people with dementia.

Dementia research and the economy

Government has recognised the huge economic opportunities created by investing in research. Their commitment to increase research and development (R&D) to £22 billion by 2024/25²¹ has been welcomed. In the recently updated government R&D Roadmap, the Government stated that **“R&D will be critical to a swift economic and social recovery from the impacts of COVID-19, for a greener, healthier and more resilient UK.”**²²

The Group agrees with this sentiment, and believes that investing in dementia research, across the entirety of the United Kingdom, will be vital to ensuring strong economic growth across all parts of the UK and contribute to the Government’s levelling up agenda.

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.²³

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.

Furthermore, a study by Policy Institute showed that every £1 invested specifically in medical research delivers a return-equivalent to 25p every year, indefinitely.²⁴

By prioritising spending on dementia research, it would not just boost the economy today, but has the potential to save significant costs in the future. An Alzheimer’s Society and London School of Economics report from 2019 found that the cost of dementia care was at that point £34.7bn a year, and if no significant changes were made to the way we provide social and medical care to people with dementia, this would increase to £94.1bn by 2040.²⁵ This is largely tied to the rising age of our population and as a result a predicted increased prevalence of dementia.

Recommendation: Dementia Moonshot funding

The Government should deliver on its manifesto commitment and fund the Dementia Moonshot as soon as possible, working with stakeholders to establish a timetable for this funding to be brought forward.



Impact of Covid-19 on Dementia Research

Delays to trials

Throughout the pandemic, many laboratories have had to be closed and/or had their research suspended. Whilst non-lab-based research such as literature reviews and data analysis have been able to continue throughout, the inability to access labs has affected many projects and has heavily impacted on research productivity. Even with labs reopened and research resuming, social distancing measures mean many labs cannot operate at 100% productivity.

“a three-to-four-month closure of a lab can have an impact on work much longer than this.” – Researcher

The Group heard how preparations for research, including the growing 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, meaning such resources would have to be destroyed.

Similarly, researchers working in areas which require face-to-face contact with participants – including people with dementia, family carers and professional carers – such as drug, clinical and care intervention trials have also been severely impacted by the pandemic. Researchers whose non-trial research work relies on access to tools such as new brain scans were also impacted by pause in work caused by the pandemic. Researchers’ work has also been impacted by clinical staff being redeployed to work in frontline NHS services throughout the pandemic. An Alzheimer’s Society survey from April 2021 found that almost 25% of its funded researchers said they or another team member had been redeployed in the NHS or in frontline services in the pandemic. Much clinical research depends on the effective running of routine NHS dementia services, many of which have been seriously affected by the pandemic and will take time to return to normal.

Charitable funding decimated

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.²⁶ These charities are an important part of the dementia research ecosystem in the UK, collectively funding £1.9bn worth of research a year; this equates to 51% of all public spend on medical research, and the salaries of around 17,000 UK scientists.²⁷

The Association of Medical Research Charities, whose members include leading dementia research charities like Alzheimer’s Society and Alzheimer’s Research UK, have estimated that the pandemic has caused a shortfall in UK medical research investment of at least £310m.²⁸

Alzheimer’s Society and Alzheimer’s Research UK would usually expect to receive between them almost 400 research proposals each year, many of which would be from early-career researchers, but without government support the financial pressures caused by Covid-19 will mean these charities will be unlikely to support any new funding opportunities for early-career researchers.

The Group heard in evidence how in 20/21 Alzheimer’s Society planned to support two funding calls of approximately £3 million each, but were unable to fund either call and have not been able to support any new research since 2019.

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.

The detrimental impact of the Covid-19 pandemic on the ability of charities to fund research projects has reinforced the need for the Government to bring forward the funding from its 2019 ‘Dementia Moonshot’ pledge.

Workforce and Early Career Researchers

Over the past 10-15 years, the UK has had considerable success in attracting talent to dementia research. Between 2008 and 2015 the number of researchers working in dementia doubled to over 6,000. This was spurred on by increased funding, and leadership from government through the Prime Minister's Challenge on Dementia.

The creation of institutions like the UK Dementia Research Institute has attracted world-leading talent to the UK from across the globe. For example, during oral evidence to the Group, Prof Bart De Strooper of the UK DRI estimated that around a third of its research Group Leaders have come from overseas to work in the UK. Prof De Strooper himself moved to the UK to lead the Dementia Research Institute, being impressed by the UK's research infrastructure and ambition to be a world leader in the field.

An Alzheimer's Research UK survey conducted in September 2020 found 29% of researchers have had their funding suspended or cut because of the pandemic, while 72% said future funding opportunities have decreased. The survey also found that due to the impacts of the pandemic, including cuts to funding or the cancellation of research projects, 17% of dementia researchers were considering moving to a different field of research, with 35% thinking of moving to a different career all together and leaving academic research.²⁹

A further survey from Alzheimer's Society, conducted in April 2021, found that

67%

of respondents thought that early career researchers would have their career most impacted by the pandemic. There is a risk that the gains the UK has made in recent years to close the gap between the impact of dementia and research levels may be lost.

During the inquiry, the Group heard from researchers at different stages of their careers, who all expressed concern at the problems faced by early career researchers (ECRs).

What is an early career researcher? – While there is some debate as to the exact definition, ECRs are generally in the earlier stages of their career, though they will often have been working in the field for several years and have developed substantial experience. Typically, an ECR is a term that could describe a PhD student, through to a researcher who has had 5 years' experience since finishing their PhD and is now able to lead their own research programme with little or no input from more senior academics.

For these ECRs, 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. Nor have they been able to receive the full support and supervision from which they would usually benefit.

There was a concern amongst respondents to the inquiry that the closing of laboratories and break in research has left today's ECRs uncompetitive. Many in research fellowships, which typically last 3 years, have lost up to 12 months' work through the pandemic. There is a fear among researchers that when they apply for funding for the next stage of their career, they will not be looked on as favourably as others, who may be further along their career or those whose work had not been impacted as significantly by the pandemic, because of this lost time and experience.

Because of the limited opportunities for ECRs in the field of dementia research, funding opportunities are highly competitive, and thus making the field less attractive to enter into. A severe lack of funding opportunities often means many researchers in the earlier stages of their career are unable to continue in the field.

Despite there being no shortage of talent and passion among dementia researchers in the UK, there is a leaky pipeline. New cohorts of PhD students are often encouraged to enter dementia research without the funding in place to ensure they can move into post-doctoral research. There is also intense competition for lectureships in the UK, which people typically apply to at the end of their postdoctoral period. This causes a career bottleneck and an exodus of researchers from the field.

Addressing these pressures will help increase the UK's research productivity. **As one researcher explained to the Group, "typical [ECR] contracts go on for 3 years, and you have to spend a lot of your time in year 3 applying for your next tranche of funding – affecting your productivity." She went on to say, "instead of concentrating on research, academics are having to worry about their mortgage."**

As a response to the Prime Minister's Challenge, in 2018 the National Institute for Health Research developed *Dementia Researcher*, an online network, website and podcast with the aim of supporting ECRs. The site shares listings of possible funding opportunities, jobs and events and shares content on relevant science, careers, and research.³⁰ Respondents to the inquiry spoke highly of *Dementia Researcher* and the support it offers to researchers in the earlier stages of their career, particularly given the lack of networking opportunities available to researchers throughout the pandemic. There was concern that funding for this site is only available until summer 2022 and without it a vital support resource would be lost.

The Government announced in May 2021 a fund of £20m to support charity-funded ECRs.³¹ But we need to see more detail in how this funding will be used and how the money will be disseminated.

Workforce and Early Career Researchers: Recommendation

- For the Government to use the Moonshot to establish a specific fund of £40m to support both clinical and preclinical postdoctoral research positions and talent retention in dementia research. This should include full fellowships and starter grants for fellows as well as support for the *Dementia Researcher* resource.



Early Detection and Diagnosis

People with dementia are often diagnosed at a time when the condition is already having a significant impact on their daily lives. An early and accurate diagnosis of dementia can empower people to access the support they need at an earlier stage, as well as ensure that they can enrol into clinical trials for new treatments, when many believe they will be most effective. Novel technologies such as the latest brain scanning techniques, novel blood tests, virtual reality, artificial intelligence, retinal scanning, and gait monitoring among others are being explored by the field to detect the very earliest signs of the diseases causing dementia. Whilst some techniques have made great progress in recent years, bringing us closer to a blood test for Alzheimer's disease, there is still much to be done to validate techniques and ensure they are fit for purpose. Further funding is needed to bring a new diagnostics test to the clinic.

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. For example, the facilities which enable PET scanning - a technique often used to validate a pre-symptomatic diagnosis - are limited to 30 locations across the country. Because of this, any new treatments that are approved may not be meeting their full potential, given that many people will be diagnosed later in their disease progression when treatments might be less effective. To combat this, 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.

Furthermore, 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. To achieve this, the UK needs to establish and encourage a critical mass of researchers, who stay in the field to work on this.

Case Study: EDoN

Early Detection of Neurodegenerative diseases (EDoN) is an initiative led by Alzheimer's Research UK. It aims to develop a digital tool that enables the detection of specific dementia-causing diseases such as Alzheimer's 10-15 years earlier than we can today.

EDoN will identify behavioural and physiological measures that demonstrate subtle changes in the earliest stages of diseases such as Alzheimer's. Around 30 different aspects of behaviour will be assessed, including sleep patterns, fine motor movement, memory, mood, navigation, and gait. These behavioural measures will be collected in thousands of research volunteers using inexpensive, non-invasive tools already present in our day-to-day lives, such as wearable devices and mobile apps. Experts in machine learning will link these digital measures to clinical data, such as brain scans, to identify patterns of change in the digital data that appear when a person shows the earliest biological signs of a disease like Alzheimer's. This will ultimately make it possible to detect signatures of specific dementia-causing diseases 10-15 years before noticeable dementia symptoms arise.

Early Detection and Diagnosis: Recommendation

- Moonshot funding should be directed towards the development of novel methods for early diagnosis, such as blood and other biomarkers for different types of dementia. Relevant systems must also be prepared to roll out these tests for wide use when validated.
- The Government should work with medical research charities to develop and fund a Longitude Prize for dementia, which would support the development of novel technologies and help to ensure that the UK is at the forefront of developing technology for people with dementia and their carers.



Prevention

Understanding how dementia can be prevented is key to ensuring that people can live their lives, as they want to live them, for as long as possible.

Despite the knowledge of these risk factors, there is generally little understanding amongst the public in 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. This is far behind equivalent figures for conditions such as diabetes and heart disease (81% and 77% respectively).³⁴

Government should take greater steps to publicise the links between these risk factors and dementia. There have been many government-funded campaigns around the steps people can take in reducing heart disease, cancer, and obesity. A better understanding of these risk factors and the steps that can be taken by individuals to reduce dementia risk or delay its onset would lead to other benefits. For example, better risk factor management could lead to fewer cases of obesity, smoking or physical inactivity, which would in turn result in fewer cases of respiratory or heart disease.

Brain Health Scotland is an organisation developed with Alzheimer Scotland and funded by the Scottish Government which provides expert advice about brain health research, policy, and healthcare, and promotes the benefits of positive brain health, including how people can reduce dementia risk. Through programmes such as educational outreach, health promotion campaigns, and working with employers, the organisation works to increase understanding amongst the population of the management of dementia risk factors.

Prevention: Recommendation

- For the newly created Office for Health Promotion to launch public information campaigns to explain how the public can take steps to reduce their dementia risk, and to generally increase people's understanding of dementia.



Case Study: Prevention within sport

A particular area of research within the field of prevention which has garnered public attention over the past several years has been the potential links between brain injuries sustained in sport and dementia.

In 2021, the Digital, Culture, Media, and Sport Select Committee held an inquiry into these links and investigated the funding and coordination of research into this area, including whether there is enough understanding of risks in youth, grassroots, and elite level sport.

As part of this inquiry, the Group also investigated the issue, and heard from leading researchers, as well as a participant in the PREVENT programme, former England international rugby player, Ben Kay. The PREVENT programme is an Alzheimer's Society-funded 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. By following elite sportspeople, the research team also hope to better understand if their involvement in sports may have affected their risk of developing dementia.

Funding research such as the PREVENT programme is vital to understanding how lifestyle factors in our midlife may influence our risk of dementia and to delve into the potential links between dementia and sport. This will allow people playing sports to make informed choices and enable risk-mitigation steps to be implemented.

The Group heard from experts in the field who said that whilst more research in this area would be helpful, we already know enough to enable government and sports bodies to act now. For example, the FIELD study on footballers – which looks at life-long health, not just dementia, found that footballers were 3 times more likely to have degenerative brain disease and 5 times more likely to be at risk of Alzheimer's disease than the rest of the population.

While much media attention has been given to the links between dementia and certain sports, it should be noted that these links have only been so far shown to apply to elite sport. There is significant evidence that for the wider population, keeping active, including through sports, is of huge benefit both in terms of preventing the onset of dementia but also a range of other health conditions.³⁷

Biomedical Research

Targeted investment and initiatives over the past decade have vastly improved the state of biomedical research into dementia in the UK. The Prime Minister's Challenge on Dementia set a target for research to identify treatments for dementia by 2025.³⁸ The 2017 creation of the UK Dementia Research Institute (UK DRI) exemplified the UK's ambition to achieve this.

The UK DRI has over 650 researchers working towards treatments and technologies to improve the lives of people living with dementia, with sites across all parts of the UK, including London, Cardiff and Edinburgh. Jointly founded by Alzheimer's Society, Alzheimer's Research UK, and the Medical Research Council, UK DRI researchers work on discovering the causes of dementia and setting paths for new treatments and cures. Its reputation as a global flagship institute has helped draw leading academics and new talent to the UK to conduct their research. The Group also heard how the UK DRI's discovery science is building a translational portfolio attracting industry investment and launching spinoffs.

“In the UK DRI, we have the rocket, we just need government to provide the fuel [with the Moonshot funding]” Prof Bart De Strooper, Director UK DRI.

Like many research institutes and universities in the UK, UK DRI sites were heavily impacted by the pandemic, with all labs having to shut, causing delays estimated between six months to one year. The pandemic also caused a very significant reduction to the funding available for the Institute from its charitable founders, who have been hit hard financially. With government funding for UK DRI running up to 2023, at which point progress will be reviewed by UKRI, it is important that this vital asset in the UK's research ecosystem is supported to continue its work.

The UK's strength in dementia research comes from its breadth, depth and diversity. Outside of the UK DRI, there are many great centres in the UK carrying out important biomedical research. Institutions across the UK, such as the UCL Dementia research centre and Sheffield Institute of Translational Neuroscience (SiTraN),

among others, are world leading and need to be supported by Government to ensure that they are not lost.

In the spring of 2021, the United States Food and Drug Administration approved the use of the first new drug for Alzheimer's disease in more than 20 years. Whilst questions remain over the efficacy of Aducanumab³⁹, the emergence of this new drug demonstrates that progress is being made, renewing focus of researchers, investors and research institutions, whilst also hopefully encouraging private sector investment in the field.

Despite this progress, respondents to our inquiry expressed concerns that clinical trials – which often provide the biggest breakthroughs in research – 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 Group also heard that steps could be taken to speed up trials. For example, a lesson learned from Covid trial acceleration is that with the participant's consent, we could integrate information about the trial with information that the NHS already holds about them. This is something that should be carried through into everyday dementia research.⁴⁰

Embedding clinical research into the patient pathway would help to ensure that patients diagnosed with dementia are given better opportunities to engage with research and help to address the issue of inequality of access.

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 life-changing treatments. There is an increasingly rich industry pipeline, with over 150 clinical trials for potential dementia treatments. With the right government support, the UK can capitalise on this surge of momentum in the dementia clinical trials space, further enhanced by the FDA's approval of aducanumab and the impact demonstrated during COVID-19.

The UK has the potential to become a driving force in developing new dementia treatments. In order to attract clinical trials and become global leaders in this area, there must be improvements in the trial set up procedure to allow trial organisers to easily identify and recruit potential participants. Development of a network of high performing trial sites with a centralised entry point would increase the speed and scale of set up, improving participant recruitment and ability to effectively run phase IV trials. These sites should seek to enhance existing collaboration, including the NIHR clinical research network to prioritise the most promising clinical research. A range of sites across many locations in the UK would ensure a greater diversity of participation.

The current knowledge gap in dementia should be addressed through sustained funding of discovery science at the UK DRI, on which later stages of research (translational and clinical) rely for the generation of essential knowledge. While bringing together sites with the infrastructure and capacity to run Alzheimer's disease clinical trials into a single network and centralised entry point for trial organisers, would streamline patient recruitment and enable speed and scale of trial set up, attracting significant life sciences investment, and helping UK patients get early access to promising treatments.

Biomedical: Recommendation

- **Government Moonshot funding should be used to entrench the UK's global leadership in biomedical, and translational and clinical dementia research by confirming appropriate funding for the UK Dementia Research Institute for the next 10 years and developing infrastructure to speed up dementia trials. This will ensure we can continue to see fundamental research on understanding the causes of dementia in the UK, and move us towards new targeted treatments and ensure that life-changing breakthroughs reach patients.**



Participation

Throughout the inquiry, the Group heard from academics, people living with dementia, and carers of those living with dementia explain the value of participating in research. It was found that despite the high value many place on research participation, there are insufficient opportunities or awareness of how people with dementia can get 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, 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. A poll by YouGov, commissioned by Alzheimer's Research UK in 2015, found that whilst 62% of the public would be willing to take part in dementia research, 81% stated they would not know how to volunteer.⁴¹

It is far more routine for cancer patients in NHS to be offered the opportunity to take part in research efforts. In 2019/20, 98,110 patients were recruited to cancer trials through the National Institute of Health Research's Clinical Research Network, against just 16,398 for dementia.⁴²

“Too often research feels something that is just done to someone, rather than something that people can be a part of” – Alzheimer's Society Research Network Volunteer.

Join Dementia Research (JDR) is a service, developed by the National Institute for Health Research and in which Alzheimer's Society and Alzheimer's Research UK are partners. It allows people to register their interest in participating in dementia research and be matched to suitable studies.⁴³ Since its inception, 50,000 individuals have signed up to the service and there have been 48,000 enrolments onto dementia studies.⁴⁴

As a part of the 2020 Dementia Challenge, the Government set out an ambition to have 25% of people living with dementia registered with Join Dementia Research⁴⁵. However, just 2% of people living with dementia in England have registered on the site⁴⁶, despite the policy being written into NHS commissioning guidance and NICE guidance.^{47,48}

Respondents to the inquiry regularly quoted the good work done by Join Dementia Research, and it was highlighted as one of the best ways to involve people living with dementia in research. However, there are also challenges to using the online system and improvements should be made to ensure it is simple, streamlined and dementia-friendly to ensure that we maximise both the number of researchers registering their studies and the number of people who register to take part in research.

The partnership behind JDR is exploring how they can improve the service, but the main barrier to effectiveness is the limited number of people diagnosed with dementia who are on the database. Moving JDR to an opt-out model and developing better data integration with NHS records would dramatically improve both the size and diversity of potential participants. Crucially, this could dramatically improve trial recruitment by providing a database of a rich cohort of people across the spectrum of dementia related diseases.

Case Study: Jane, Alzheimer's Society Research Network Volunteer

Jane, a former satellite engineer, cared for her mother whilst she was living with dementia, and has served as an Alzheimer's Society Research Network Volunteer for the past 8 years. Jane supports academics in their research, serving as a monitor on several projects within care and biomedical research. Jane shared her experiences of supporting research and felt that it gave her a sense of empowerment to know she was supporting such important work. Jane said that caring for a loved one with dementia can give you the feeling that **“everything changes and you have no control over what's going on. Becoming involved in the Research Network and starting to do work with researchers helped me to feel I was taking a bit of control back. I was doing something that wasn't going to directly help Mum...but it would be a legacy, something that would in the future change...the lives of people.”**

Involvement in research can be further boosted by ensuring that possible participants are properly informed of the opportunity to take part, through discussions with health professionals, or even through the sharing of literature. For example, the Group heard in evidence how the NIHR's Office of the National Director for Dementia Research ran a pilot scheme in 2018/19 to test the success of writing letters to newly diagnosed people with dementia, including postal application forms to register their interest in taking part in research. The Group heard evidence how this system increased participant registrations by 6-8%, and when combined with dedicated NHS staff time to discuss the service and support completion of application forms, sign-up rates reached 25%.

Participation: Recommendation

- **The Government should work with Join Dementia Research and NHS authorities to maximise the success of JDR as a mechanism for simply and quickly matching eligible patients to relevant studies, by:**
 - a) **moving JDR to an opt out model. All newly diagnosed patients should receive a letter from the NHS within 3 months of their diagnosis providing information about how they can take part in dementia research and the option to leave the database if they wish.**
 - b) **addressing data gaps by integrating JDR with electronic patient records. This would build on infrastructure developed by Dementia Platforms UK and Health Data Research UK to harmonise data across trial cohorts and link research data with clinical data. It would act as a mechanism to collect long term data on participants and track patient outcomes.**



Care Research and Technology

When someone visits a doctor's surgery or hospital for medical treatment, they can reasonably expect that this treatment will be evidence-based. This isn't the case for care services, where very few services or approaches to care are based on tested evidence.⁴⁹ This further compounds the inequity between those who rely on care services versus those who rely on health services.

Research into understanding how people with dementia and their carers can be best supported is vital. While as a society we can often see biomedicine as the 'key' mode of research to help people in the future, care research can offer us the opportunity to help people with dementia today and in the future. Through care research, new technologies and treatments can be used more effectively, and people with dementia can be better supported, for example by aiding them to live independently or with minimal support for longer.

Case Study: Alzheimer's Society Centres of Excellence

In 2017, Alzheimer's Society partnered with leading academics to establish and fund three Centres of Excellence for dementia research and care at universities across the UK: Newcastle, Exeter and University College London. These centres were developed to focus on ways to measure and improve quality of life as well as access to post-diagnostic support.

The IDEAL project⁵⁰, based at the Exeter University Centre of Excellence, examines influences on quality of life and wellbeing for people living with dementia and family carers, and has identified a range of factors that may impact on quality of life for people with dementia. The researchers found that factors of optimism, self-esteem, loneliness, and depression are important in influencing how people with dementia are able to live well.

The Group highlighted this model of supporting Centres of Excellence as being particularly impressive and impactful.

The use of new technologies to support carers and increase the independence of people with dementia offers many opportunities. However, the Group heard in oral evidence from Alzheimer's Society that often the routes open to test, develop, and bring these technologies forward to scale are not always clear and funding for this type of research is limited.

The Wellbeing and Health for People Living with Dementia (WHELD) project, funded by the NIHR, starkly demonstrated this lack of evidence-based care. In a review of 170 training manuals for person-centered care in dementia, researchers found that just four provided evidence that methods had worked when tested in a research setting.⁵¹

The Alzheimer's Society Dementia Care Summit, held in 2020, brought together over 80 leading researchers, clinicians, and policy makers. It found that the biggest barrier in care research is the implementation of already known findings.⁵²

Targeted funding can ensure we're able to embed this learning through implementation programmes, such as STrAtegies for RelaTives (START), an Alzheimer's Society funded implementation programme run by researchers at University College London that aims to reduce depression and anxiety among carers of people with dementia.⁵³

The Group heard from the Director of the UK DRI Care, Research and Technology centre, based at Imperial College London, Professor David Sharp, that 25% of hospital beds are currently taken up by people living with dementia, but new technologies that monitor people in their homes can enable the early identification of risks such as sleep disturbance, incontinence, or infections. The early detection of these risks could enable people with dementia to live at home safely for longer. The Group heard that greater funding would enable a more integrated approach and trials to occur on a much bigger scale.

Care research and technology: Recommendation

- The Moonshot funding should be used to build on the success of the multidisciplinary approach of the Alzheimer's Society's Centres of Excellence model. Further expanding it by introducing 3 new centres that will focus on some of the biggest challenges in dementia research that can have the biggest impact on the lives of people affected by dementia. This could include translation and implementation of research.



Conclusion

Increased investment and leadership from the Government in dementia research has the potential to provide incredible opportunities for the growth of our economy, and to vastly improve the lives of people living with dementia and their loved ones.

This report has found that there are many examples of extraordinary breakthroughs and research being conducted in the UK, but with further support from government, the UK could cement its place as a world leader in the field.

The inquiry has found that there are areas which are in desperate need of extra support, for example Early Career Researchers. The Government should use the Dementia Moonshot to provide this support and ensure that the UK can attract and produce the world's leading dementia researchers.

The recommendations in this report seek to increase productivity and empower people with dementia to involve themselves in research.

The effects of the pandemic have only highlighted further the urgent need for the Government to bring forward the promised Dementia Moonshot funding. With it we can truly improve the lives of people affected by dementia through research.



Appendix

Methodology

In March 2021, the APPG launched an inquiry into the state of dementia research in the UK. The inquiry included a call for both written and oral evidence from anyone with an interest in dementia research – professional and personal.

The Officers of the APPG on Dementia would like to thank the following respondents for giving oral evidence to the Group:

Jane Ward, Person with lived experience and Alzheimer's Society Research Network Volunteer

Professor Martin Rossor, National Dementia Director at National Institute for Health Research

Professor Dame Louise Robinson, Professor of Primary Care and Ageing

Professor John O'Brien, Professor of Old Age Psychiatry

Professor David Sharp, Centre Director of UK DRI Care Research & Technology

Dr Willie Stewart, Consultant Neuropathologist at the Queen Elizabeth University Hospital, and honorary Associate Professor at the University of Glasgow

Professor Craig Ritchie, Professor of the Psychiatry of Ageing, Director of Brain Health Scotland, and Director of the Centre for Dementia Prevention

Professor Gill Livingston, Professor of Psychiatry of Older People

Professor Selina Wray, Professor of Molecular Neuroscience

Jennifer Bute, Person with lived experience and Alzheimer's Society Research Network Volunteer

Dr Sarah Ryan, Alzheimer's Society Junior Fellow

Dr Paresh Malhotra, Clinical Reader in the Division of Brain Sciences and Consultant Neurologist

Professor Bart De Strooper, Director at UK Dementia Research Institute

David Thomas, Head of Policy at Alzheimer's Research UK

Fiona Carragher, Director of Research & Influencing at Alzheimer's Society

Ben Kay, former professional rugby player, commentator and participant in the PREVENT research program

The Officers of the APPG on Dementia would like to thank the following respondents for sharing written evidence with the Group:

Cognitive Function and Ageing Studies collaborative research group, University of Cambridge

Alzheimer's Research UK

Association of Medical Research Charities

Centre for Dementia Research, Leeds Beckett University

Clinical Research Network: North West Coast (National Institute of Health Research)

Dr Ben Underwood, Consultant Old Age Psychiatrist and Lecturer in Older Peoples Health

Dr Naaheed Mukadam, Principal Research Fellow and Consultant Old Age Psychiatrist

Executive Committee of the Faculty of Old Age Psychiatry, Royal College of Psychiatrists

Global Brain Health Institute

Housing Learning and Improvement Network

Innovations in Dementia

NIHR Dementia Strategy Group

Parkinson's UK

Professor John Keady, Professor of Mental Health Nursing and Older People

Professor John O'Brien, Professor of Old Age Psychiatry

Royal College of Speech and Language Therapists

The IDEAL Programme

The Lewy Body Society

UK Dementia Research Institute

Clarissa Giebel, Research Fellow

Professor Gordon Wilcock, Emeritus Professor of Gerontology

Willy Gilder, Person with lived experience

Professor Claudia Cooper, Professor of Psychiatry of Older Age

Dr Ryan West, Principal Investigator / Research Fellow

Simon Ridley, Scientific Research Strategy Manager

Robyn Dowlen, Postdoctoral Research Associate

Prof Joanna M Wardlaw, Professor of Applied Neuroimaging

Adam Smith, Programme Director

Margaret Booth, Volunteer

The inquiry also took evidence from a number of people affected by dementia and academics who wished to remain anonymous.

Thank you also to Jordan Clark, Tom Redfearn, Dr Richard Oakley and Hannah Churchill, and all of Alzheimer's Society for their help in managing the inquiry and drafting this report.

If you would like to find out more about this report or inquiry, please contact appgondementia@alzheimers.org.uk

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The All-Party Parliamentary Group (APPG) on Dementia is a group of cross-party parliamentarians with an interest in dementia. It was created to build support for dementia as a publicly stated health and social care priority, in order to meet one of the greatest challenges presented by our ageing population.

The APPG prides itself on remaining at the forefront of debates on the future of dementia care and services. Over the past ten years we have run parliamentary inquiries into key issues affecting people with dementia, their families and carers.

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[alzheimers.org.uk](https://www.alzheimers.org.uk)

appgondementia@alzheimers.org.uk

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