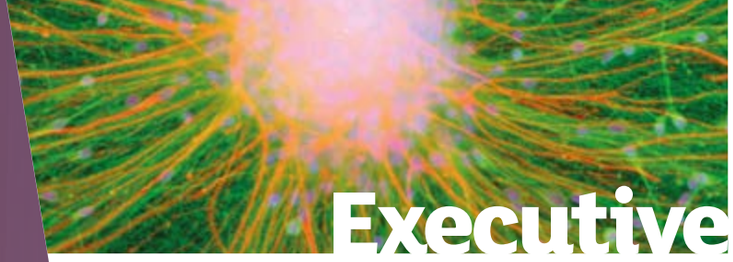
Delivering the Dementia Moonshot

A plan to find life-changing treatments

Alzheimer's Research UK

Make breakthroughs possible



"We cannot continue to underfund dementia research and be surprised when better treatments aren't available for people living with the condition"

Dr Helen Beaumont,
Alzheimer's Research UK Champion.

Foreword

I had a deeply personal reason for becoming a dementia researcher. My husband Clive was diagnosed with frontotemporal dementia aged just 46 and died aged 51. We struggled for years to get a diagnosis – for a long time, doctors refused to acknowledge that a healthy man in his early 40s could have dementia. When we finally did get a diagnosis, there was no treatment and very little support.

At the age of 58, after our children had left home for university, I moved from Oxford to Manchester to pursue dementia research. I completed a PhD and now specialise in using MRI (magnetic resonance imaging) to investigate brain changes in people with dementia, with the aim of improving diagnosis. I'm determined to ensure other families don't have to go through the years of anguish we went through.

Clive was diagnosed in the early 1990s, and nowadays things are little different. Though GPs are becoming more aware that dementia can affect people under 65, we still don't have a test for frontotemporal dementia. We still don't have a treatment that will stop or slow the progress of any of the various forms of dementia.

We must do more to support people caring for loved ones with dementia, but that alone is not a solution to the real issue. We cannot continue to underfund dementia research and be surprised when better treatments aren't available for people living with the condition. Until we have the right tools to identify the diseases that cause dementia early and can effectively treat those diseases, we aren't going to see the burden lifted from families across the UK or our struggling social care system. My family deserved better, and so do the families going through this today.

In the 2019 general election, the Conservatives pledged to double investment in dementia research and use the funding to launch a 'Dementia Moonshot' programme[i] with the ambition of finding a cure for dementia. Alzheimer's Research UK's plan outlines the ways in which this additional investment should be channelled to accelerate progress towards new treatments by finding new ways to detect dementia at its earliest stages, establishing methods to accurately measure whether a potential drug is proving to be successful, and developing a group of 'trial ready' volunteers ready to take part in research.

It also makes the crucial point that without this additional large-scale investment we risk losing some of the best and brightest scientists from the field. My personal experience is that around a quarter of the people who were working in dementia research alongside me when I started my career have since left academia or moved to better-funded research fields. This is a loss we simply cannot afford.

Dementia is caused by diseases in the brain. We have a good idea of what is involved, and we have good ideas about how we can interrupt that process. With the right support from government, I am positive that is possible. I have great faith in human ingenuity.

Dr Helen Beaumont,
Alzheimer's Research UK Champion

Dementia is the healthcare crisis of our time

By 2021, over one million people in the UK will be living with dementia, and the condition will cost our economy a staggering £30bn each year.[ii] Much of this cost will be carried by individuals themselves, family carers and the overstretched social care system. With an ageing population, and no treatments that can prevent, slow or cure the diseases that cause dementia, this figure is set to double by 2050.[iii] Now the leading cause of death in the UK, dementia has a devastating impact on individuals and their families.

Finding life-changing treatments is the only long-term, sustainable solution to this crisis.

In recent years, government investment, such as into the UK Dementia Research Institute, has helped to significantly grow dementia research capacity and put in place the infrastructure to increase groundbreaking research. However, dementia research and treatment lag far behind other major disease areas, such as cancer and HIV. If we are to catch up and bring about life-changing treatments as soon as possible, we need to be conducting far more research.

That is why Alzheimer's Research UK has pledged to commit £250m to dementia research by 2025. However, we cannot do it alone.

The positive commitment in the 2019 Conservative manifesto[iv] for a new 'Dementia Moonshot' with £1.6 billion for dementia research over the next decade is an encouraging step forwards towards more progress for people with dementia and their families. The commitment to double current research funding in dementia and speed up trials for new treatments is welcome news.

We now need to see action to deliver on those commitments. The UK urgently needs an ambitious dementia research funding settlement from government to ensure we capitalise on the momentum to date. It is only with a step change in investment that we will be able to rapidly accelerate towards the new treatments we desperately need.

In 2018, we published **No Time to Lose: An Action Plan for Dementia**, identifying priority areas for this investment in order to bring about life-changing treatments for dementia. Alzheimer's Research UK's new plan builds on these priorities, outlining the actions government must take in order to deliver its 'Moonshot' ambition of finding a cure for dementia.

Now is the time to deliver political leadership that puts UK dementia research at the forefront of the global search for life-changing treatments and paves the way for breakthroughs that will transform the lives of people with dementia and their families across the UK.

Priorities to deliver the Dementia Moonshot

1 Find ways to detect the diseases that cause dementia 10-15 years earlier, to broaden the search for new treatments and intervene with those most at risk of developing dementia.

• Build on current investment to discover novel methods to detect changes in the brain that occur at earlier stages of disease progression, ideally 10-15 years before the onset of the clinical symptoms of dementia.

• Government to support Alzheimer's Research UK's 'Early Detection of Neurodegenerative Diseases', an initiative to develop a digital tool to detect early changes in the brain, taking the tool from creation to validation, including through clinical trials.

2 Find ways to more effectively validate novel targets in early drug development to maximise chances of successful clinical trials.

• Establish a 'Dementia Translational Medicines Accelerator', a fund dedicated to testing the promise of drugs in very early clinical trials for dementia. This will help us to better predict whether emerging medicines will be successful at later stages of clinical trials by providing tools that monitor a drug's ability to get to and affect the right part of the brain. Ultimately, the accelerator aims to save money in the hunt for much needed new treatments by weeding out those that are unlikely to work at the earliest stages of clinical development.

3 Make the UK the best place to conduct clinical dementia research.

• Invest in an infrastructure that brings together existing cohorts (including people registered with Join Dementia Research and Dementias Platform UK data) to establish a single enriched "trial ready" cohort, including information on a baseline of key tractable biomarkers.

• Increase research funding to develop and retain clinical dementia academics, thereby positioning the UK as a global leader in conducting clinical research.

• Based on the outcome of existing initiatives, establish a strategy that supports research in a real world setting by expanding the infrastructure for Brain Health Clinics and boosting the research capacity of existing memory clinics.

4 Expand research infrastructure to maintain the UK's position as a world leader in dementia research.

• Support emerging science and centres of excellence for dementia research, such as those supported by the Northern Health Science Alliance, that are less well represented in this research space. The priorities should be to capture interdisciplinary expertise, support diversity and accelerate collaboration across the UK.

• Maintain government investment in UK Dementia Research Institute (UK DRI) beyond the current commitment to 2023.

5 Further our understanding of dementia risk reduction and prevention and dementia in the context of multi-morbidities.

• Learn from and build on existing longitudinal studies relating to dementia, which will further our understanding of emerging risk factors for dementia, such as hearing loss and cardiovascular health.

• Fund research that mines existing data platforms (including, but not limited to, Dementias Platform UK and Accelerating Detection of Disease (ADD)) to better understand dementia in the context of multi-morbidities.

6 Develop robust prevalence data for dementia to further our knowledge of the impact of dementia across our society.

• Government leadership and investment to initiate and develop new dementia prevalence research.

• Regular data collection in supplementary areas such as young onset and ethnicity.

Now is the time to invest in dementia research.

Since 2017, dementia has been the leading cause of death in the UK.[v] Age is the biggest risk factor, and with an ageing population, current projections anticipate that by 2021 there will be over one million people living with dementia in the UK, rising to two million by 2050.[iii]

The economic impact of dementia to our society each year is £26 billion,[ii] more than cancer and chronic heart disease combined, with over 80% of the cost carried by social and informal care. For people with a disease that causes dementia, symptoms worsen and quality of life deteriorates as the disease progresses – eventually reducing their ability to perform everyday activities and resulting in loss of independence and lack of interaction with the wider world.[vi]

A 2018 poll shows that UK adults believe dementia is in the top three health areas the NHS should focus on in the next 10 years.[vii] Yet we currently have no way to delay the onset, slow progression or cure the diseases that cause dementia.

Where there has been substantial and sustained investment in medical research for other major disease areas, such as cancer and HIV/AIDS, we have seen treatment breakthroughs and subsequent increases in life expectancy.

Dementia research requires similar levels of investment if we are to make the same life-changing breakthroughs.

Government investment in dementia research was just £82.5m in 2017/18,[viii] equivalent to 0.3% of the total annual cost of dementia. By contrast, government funding for cancer research stood at £269 million in 2015/16 - 1.6% of cancer's £16.4 billion annual cost to the UK. Due to this lack of investment, dementia is lagging decades behind other major disease areas in terms of research and treatments.

Without new interventions, the dementia crisis will continue to worsen. The government's commitment to double current funding for dementia research, while also setting an ambition for a 'Dementia Moonshot', gives an unparalleled opportunity for the government to find sustainable and lasting solutions to one of the greatest healthcare challenges of our time. However, this will only be successfully delivered if the additional funding is channelled into the areas of greatest unmet need.

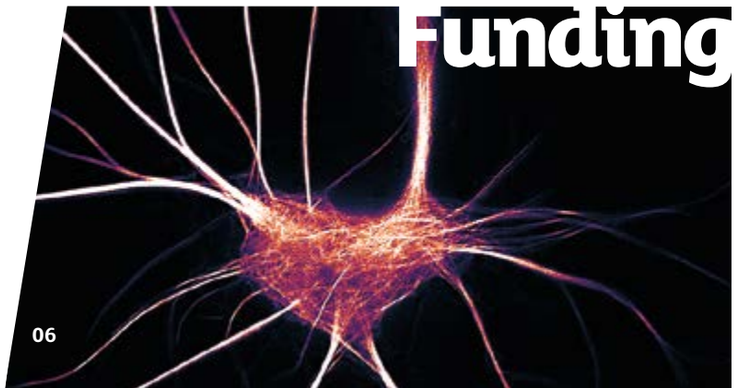
Retaining the UK's position as a global leader in dementia research

To date, dementia research has been a success story for the UK government. Through the 'Challenge on Dementia', investment has been made in initiatives such as the UK Dementia Research Institute (UK DRI), Dementias Platform UK[ix] and the Dementia Discovery Fund. These are providing the foundations for world-leading research infrastructure – advancing our knowledge and understanding of the diseases that cause dementia and helping us move towards life-changing treatments faster.

This investment is making a difference. Today we understand the diseases that cause dementia better than ever before. The field of neuroscience is advancing rapidly as scientific techniques such as neuroimaging improve and our understanding of processes in the brain grows.[x] We now know that changes in the brain begin decades before the overt symptoms that we currently associate with dementia present.

However, we need to broaden our search for new treatments beyond the specific approaches which have been the focus of many drug trials to date. There are potential new drug targets emerging, such as neuroinflammation, DNA repair mechanisms and synaptic health. As initial investment begins to bear fruit, additional capacity is required to ensure that the UK continues to be at the forefront of the science that may lead to the first life-changing treatments for dementia.

As well as the benefits for people with dementia across the UK, the successful delivery of the government's 'Dementia Moonshot' will help secure the UK as a world leader in dementia research. This will put the UK on the front-foot to capitalise on emerging detection and diagnostic technologies, identified as a priority area in the government's Grand Challenge on Artificial Intelligence and Data.[xi] Government signalling this as an important area for the life sciences economy will encourage inward investment and make the UK an attractive place for the best researchers from across the globe to live and work.



Priority Funding Areas

1. Find ways to **detect the diseases that cause dementia 10-15 years earlier**, to broaden the search for new treatments and intervene with those most at risk of developing dementia.

Introduction

Most potential treatments for Alzheimer's disease, the most common cause of dementia, have so far failed to show efficacy in phase III clinical trials. One potential explanation is that these interventions are being trialled at too late a stage in the disease process. Currently, recruitment to clinical trials occurs at the onset of dementia symptoms, which is decades after early changes occur within the brain.

There is a consensus that many age-related conditions, including dementia, cancer and osteoarthritis, are better treated if they are detected early. A recent report from Alzheimer's Research UK highlighted that 74% of people would want to know if they had Alzheimer's disease before symptoms develop.[xii]

The government's Accelerating Detection of Disease programme, working with industry and charities including Alzheimer's Research UK, aims to detect diseases earlier and will develop diagnostic tools using artificial intelligence. While this is an important step forward, given the complex nature of the diseases that cause dementia and a lack of low cost, effective detection tools, other actions are urgently required so we can detect very early changes in the brain.

Creating early detection tools

We believe that the creation of a low-cost clinically validated tool, suitable for use in clinical practice, would mean that we could detect the diseases that cause dementia 10-15 years earlier than we can today.

If an early detection tool was accepted and implemented throughout the NHS, such as in regular health checks, this would enable individuals to better understand and manage their risk, volunteer for clinical trials and be best placed to benefit from new treatments.

An early detection tool would also support the stratification of patients for further diagnostic testing (e.g. using fluid biomarkers or neuroimaging) and could enable more informed recruitment into suitable clinical trials. We know that three quarters of the public are willing to undertake most forms of testing if it could help identify their risk of developing the diseases that cause dementia.[xii]

Early detection also enables individuals to better manage their risk of developing dementia through addressing modifiable risk factors. Without improved patient stratification, we will continue to test potentially life-changing treatments in the wrong people and too late in the disease stages. At these later stages, we lose the opportunity to stratify those most at risk into clinical trials and it is too late for people to address modifiable lifestyle factors which may help prevent them from developing dementia.

We know there is appetite from the public to find out the risk of developing dementia before symptoms appear. In addition, scientists believe earlier detection could lead to undiscovered avenues of research and potential new approaches to drug development. Given this public appetite for earlier knowledge, coupled with the scientific imperative for earlier detection, government must address this urgently and invest in finding ways to detect the diseases that cause dementia much earlier.

What action do we need?

i. Build on current investment to discover novel methods to detect changes in the brain that occur at earlier stages of disease progression, ideally 10-15 years before the onset of the clinical symptoms of dementia.

ii. Alzheimer's Research UK is launching the 'Early Detection of Neurodegenerative Diseases' initiative, working with partners to develop a clinically-approved digital tool to detect the early stages of the diseases that cause dementia. The tool will utilise data collected longitudinally from inexpensive and non-invasive wearable technology to detect early changes in the brain. Government should support the initiative, taking the tool from creation to validation, including through clinical trials.

Actions and costs

	ACTION	ESTIMATED COST
1	Government support for 'Early Detection of Neurodegenerative Diseases' initiative	£20 million over five years

2. Find ways to more effectively **validate novel targets in early drug development** to maximise chances of successful clinical trials.

Introduction

To increase our chances of translating the discoveries made by researchers into novel treatments, new drug targets need to be authenticated using both pre-clinical models (e.g. in animal and stem cell systems) and early clinical trials.

The high failure rate of dementia drug discovery over recent years has acted as a disincentive for pharmaceutical companies to invest in this high-risk field. Strategic partnerships, such as the Dementia Consortium, a group of pharmaceutical companies coming together to share the cost and risk of funding early dementia drug discovery, and the Dementia Discovery Fund, a £250m venture capital fund, are helping to stimulate activity in this area.

However, while we can find ways to stimulate research investment, if we are to take new drug targets through the drug development process we need to do more to develop better measures that will validate target engagement in early phase clinical trials. This will maximise the chances of successful outcomes and reduce the likelihood of expensive later stage trials failing.

Speeding up trials for new treatments

The rapid translation of new ideas being taken into clinical trials improves our chances of bringing about life-changing treatments for dementia sooner. However, there are measures we can take to better test target validation and robustness that will improve our understanding of why existing strategies have failed and inform more effective and rational approaches for future investment and drug design.

Dementia research has suffered from historic underinvestment, and has been hampered by a perception that it is a high cost/high risk drug discovery field. The high failure rate of successful drug development to date means there is a lack of incentive to invest in this vital work. Without robust target validation in the early pre-clinical and clinical stages of drug development, we will continue to fail to overcome barriers to novel drug discovery and development.

Early target validation will help inform decisions to "kill or keep" potential new drugs in the earlier phases of the clinical trials process. This will mean only validated targets are taken forward into expensive later stage trials, thus delivering significant savings to pharmaceutical companies.

What action do we need?

i. Establish a 'Dementia Translational Medicines Accelerator', a fund dedicated to testing the promise of drugs in very early clinical trials for dementia. This will help us to better predict whether emerging medicines will be successful at later stages of clinical trials by providing tools that monitor a drug's ability to get to and affect the right part of the brain. Ultimately, the accelerator aims to save money in the hunt for much needed new treatments by weeding out those that are unlikely to work at the earliest stages of clinical development.

Actions and costs

	ACTION	ESTIMATED COST
1	Establish a 'Dementia Translational Medicines Accelerator' to improve the success of dementia drug development.	£50 million over five years from government, with additional funds leveraged from industry.

3. Make the UK the best place to conduct **clinical dementia research**.

Introduction

The government's Life Sciences Industrial Strategy set an ambition to make the UK the go-to place for clinical research.[xiii] This can only be realised for dementia if we have both the clinical capacity and infrastructure, together with sufficient numbers of suitable volunteers to take part in research.

A Cross-Funder Review[xiv] in 2015 identified "difficulty in obtaining support to remain research active" as the most common barrier to progressing a clinical academic career (regardless of research area). We also know the number of clinical academics in psychiatry, one of the key specialities for treating dementia, dropped by over 20% between 2007-2017.[xv] Availability of funding is also a barrier to undertaking research and it has been demonstrated that government investment at the early clinical academic career stage, for example funding for PhD training through Clinical Research Training Fellowships, is critical to building capacity at the academic-clinical interface.[xvi]

Developing "research-ready" cohorts will also contribute to the UK being known as the best place to conduct clinical dementia research. Research-ready volunteers for dementia would be people who have been deeply phenotyped, i.e. assessed for disease biomarker status. We must invest in an infrastructure to bring together existing cohorts, build on the progress of other platforms such as Dementias Platform UK and Join Dementia Research (JDR) and establish a single enriched "trial ready" body of volunteers.

Memory clinics, as well the newly emerging network of 'Brain Health Clinics' should be used to create a unique well-resourced network that can be harnessed for research and trials, can deliver evidence-based interventions to those most at risk of developing dementia, and ultimately would be a site to deliver life-changing treatments for dementia once they are available. This kind of research-active clinic network is the missing link in delivering high quality interventions and care for people with or at risk of developing dementia.

A global leader in clinical dementia research

All health professionals should have the opportunity to undertake clinical research alongside the demands of training and service delivery. The government should allocate dedicated time and funding for clinicians to embark upon and remain on the clinical academic pathway. Evidence shows research-active hospitals have better patient care outcomes.[xvii]

We want to see a future where the UK is viewed as a world-class place to carry out clinical dementia research, with groups of trial-ready participants and research being conducted in a range of clinical settings.

We must incentivise and build a culture of valuing clinical research in the UK. This will speed up the pace at which new innovations can be incorporated within clinical practice and ensure that we maintain a highly skilled clinical research workforce.

What action do we need?

i. Invest in an infrastructure that brings together existing cohorts (including people registered with Join Dementia Research and Dementias Platform UK data) to establish a single enriched "trial ready" cohort including information on a baseline of key tractable biomarkers.

ii. Increase research funding to develop and retain clinical dementia academics, thereby positioning the UK as a global leader in clinical research.

iii. Based on the outcome of existing initiatives, establish a strategy that supports research in a real world setting by expanding the infrastructure for Brain Health Clinics and boosting the research capacity of existing memory clinics.

Actions and costs

	ACTION	ESTIMATED COST
1	Invest in an infrastructure that brings together existing cohorts (including people registered with Join Dementia Research and Dementias Platform UK data) to establish a single enriched "trial ready" cohort.	£30m over five years.
2	Increase research capacity to develop and retain clinical dementia academics.	£30m over five years.
3	Boost capacity (including for undertaking research) for existing memory clinics and establish a strategy to deliver dementia research in a real world setting by expanding the infrastructure for Brain Health Clinics.	£200m over five years.

4. Expand research infrastructure to maintain the UK's position as a world leader in dementia research.

Introduction

The recent focus and increase in funding for dementia research means that important advances have been made in our understanding of the disease mechanisms that cause dementia, particularly identifying the genetic factors that contribute to the risk of developing the condition. However, a more in-depth understanding of the cause of diseases like Alzheimer's is still fundamentally needed to inform all other parts of research into the disease pathways, such as target discovery, drug design, identification of novel biomarkers and evidence to support preventative measures.

Growing dementia research capacity

Higher levels of investment in dementia have resulted in increased researcher capacity.[xviii] However, this growth must continue to enable further progress towards life-changing treatments.

We need to see continued growth in investment in basic dementia research. The setting up of the UK Dementia Research Institute (UK DRI) in 2017 broke new ground by bringing together world leading expertise in dementia research and it will be critical for the government to continue to invest in the UK DRI as part of the 'Dementia Moonshot'.

However, if we are to further develop our understanding of the diseases that cause dementia and move the science rapidly towards finding life-changing treatments, government must also support new collaborations, interdisciplinary research and emerging centres of excellence. We need support for diversity and innovation so that the field benefits right across the UK.

What action do we need?

i. Support emerging science and centres of excellence for dementia research, such as those supported by the Northern Health Science Alliance, that are less well represented. The priorities should be to capture interdisciplinary expertise, support diversity and accelerate collaboration across the UK.

ii. Maintain government investment in UK Dementia Research Institute (UK DRI) beyond the current commitment to 2023.

Actions and costs

	ACTION	ESTIMATED COST
1	Support emerging science and centres of excellence (beyond the UK DRI) for dementia research across the UK.	£200 million over five years.
2	Further investment in the UK DRI, beyond 2023.	£200 million over five years.

5. Further our understanding of **dementia risk reduction and prevention** and dementia in the context of multi-morbidities.

Introduction

The 2017 Lancet Commission[xix] brought together existing evidence on dementia risk reduction from a range of studies and estimated that a third of dementia cases could potentially be prevented if nine different risk factors could be eliminated. As well as outlining established risk factors for dementia, which can be summarised as 'what's good for your heart is good for your brain', the report highlighted emerging evidence linking hearing loss and social isolation to dementia risk and called for more ambitious strategies for dementia prevention.

We have seen policy engagement around dementia risk reduction through the NICE guideline in 2015[xx], the recent NHS Long Term Plan and also the 2019 government green paper 'Advancing our health: prevention in the 2020s'.[xxi] However, the government's policy ambition to prevent 150,000 heart attacks, strokes and cases of dementia as outlined in the NHS Long Term Plan[xxii] may be limited by the many gaps that remain in the evidence base, and there is limited understanding of which health interventions are most effective for tackling the identified risk factors as well as the interplay between risk factors.

The risk reduction research community has faced numerous challenges due to a lack of funding, problems in sharing data between existing studies and cohorts, and disincentives for collaboration and methodological difficulties.[xxiii] We are seeing some progress in this area, boosted by initiatives such as Alzheimer's Research UK's 'Mike Gooley Trailfinders Charity Prevention and Risk Reduction Fund' but there has been an overall lack of strategic leadership from government to focus on and overcome these challenges.

Dementia risk reduction

The development of a solid evidence base, beyond known cardiovascular risk factors, will support policymakers to develop an effective public health strategy.

Individuals currently lack the knowledge that they can reduce their risk of developing dementia. Alzheimer's Research UK's Dementia Attitudes Monitor[xxiv] showed that just 31% believe it's possible to lower the risk of dementia, compared to 81% for diabetes and 77% for heart disease. We need to see a step change in attitudes towards dementia risk reduction.

The development of further evidence on dementia risk reduction would strengthen government's ability to lead a significant and wide-reaching public health risk reduction and prevention programme with targeted messages around dementia on a range of causal factors. Building the evidence base is key to our ability to inform and equip people to reduce their risk of developing dementia.

Understanding dementia in the context of multi-morbidities

Over 90% of people living with dementia have another health condition, with the most common being hypertension, painful conditions and depression.[xxv]

We also know that in the UK, people with dementia who have higher numbers of comorbidities die earlier and have considerably higher health service usage in terms of primary care consultations, hospital admissions and prescribing.[xxvi]

It is only very recently that the UK government has begun to show leadership in this area. In November 2019, the government, through the Strategic Priorities Fund, launched a research call to tackle multi-morbidity at scale.[xxvii] While this focus is welcome, given the sheer numbers of people living with dementia alongside other health conditions, the complexities of treatment and care for people living with multiple health conditions overlaid with cognitive impairment, and the impact on our health care system, we urgently require a better understanding of these complex issues and how to better manage them.

What action do we need?

i. Learn from and build on existing longitudinal studies relating to dementia, which will further our understanding of emerging risk factors such as hearing loss and cardiovascular health.

ii. Fund research that mines existing data platforms (including, but not limited to Dementias Platform UK and Accelerating Detection of Disease) to better understand dementia in the context of multi-morbidities.

Actions and costs

	ACTION	ESTIMATED COST
1	Build on existing longitudinal studies relating to dementia prevention to further our understanding of emerging risk factors for dementia such as hearing loss and cardiovascular health.	£15 million over five years.
2	Fund research that mines existing data platforms (including, but not limited to Dementias Platform UK and Accelerating Detection of Disease) to better understand dementia in the context of multi-morbidities.	£10 million over five years.

6.

Develop **robust prevalence data** for dementia to further our knowledge of the impact of dementia across our society.

Introduction

Dementia prevalence data is a vital resource needed throughout the dementia research pathway, however there are many gaps in the current evidence. We know that for the uptake of new treatments through the NHS, accurate prevalence data will be needed for economic evaluations and to assess capacity requirements.

There have been growing concerns[xviii] that current dementia prevalence data is no longer reliable, particularly at a local level. Notable existing studies, such as MRC's Cognitive Function and Ageing Study 2[xxviii] and the English Longitudinal Study of Ageing[xxix] have provided considerable insight to help with service planning and the calculation of dementia diagnosis rates. However, as well as being out of date, the current data does not reflect the full ethnic and social diversity of the UK or the prevalence of young onset dementia (<65 years). One example of this is that there is only one dementia diagnosis code for those aged under 65. The absence of robust, accurate data poses a significant gap in our knowledge of public health and hinders policy and planning across health and social care.

Better dementia data

We need a nationally representative cohort study that gives reliable and robust estimates of the prevalence of dementia and cognitive decline on a regular and ongoing basis. This would improve the accuracy of many aspects of dementia research and care, including the development and validation of new diagnostic tools, clinical trial recruitment, dementia diagnosis rates, and evaluation of new treatments as well as service planning and delivery.

Robust prevalence data is also hugely valuable as it provides greater understanding of disease progression, the differences associated with ethnicity and young onset dementia. We need to capture the diversity of dementia in the UK if we are to build our understanding of the condition.

Without robust and up to date prevalence data many aspects of dementia research and care will continue to be undermined.

What action do we need?

i. Government leadership and investment to initiate and develop new dementia prevalence research.

ii. Regular data collection in supplementary areas such as young onset and ethnicity.

Actions and costs

	ACTION	ESTIMATED COST
1	Funding for a national representative cohort study to provide reliable and robust estimates of prevalence of dementia and cognitive decline.	£5 million to develop cohort and data collection, plus £500k for supplementary data collection.

About Alzheimer's Research UK

Alzheimer's Research UK is the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

Our mission is to bring about the first life-changing treatment for dementia by 2025. To make this a reality, we focus on four key areas: understand, diagnose, reduce risk and treat.

We have pledged to commit a further £250m to fund life-changing dementia research by 2025, including:

• The 'Early Detection of Neurodegenerative Diseases' initiative, a global platform to enable very early detection of the diseases that cause dementia, ultimately transforming the search for life-changing preventions and treatments.

• The Psychiatry Consortium, a charity and industry partnership between Alzheimer's Research UK, MQ: Transforming mental health, Medicines Discovery Catapult and six pharmaceutical companies, which focuses on identifying and validating novel drug targets for behavioural symptoms affecting people with mental health conditions and dementia.

• The second phase of the Dementia Consortium, a unique charity and industry collaboration led by Alzheimer's Research UK, which validates novel dementia drug targets emerging from academia and accelerates the translation of these findings into early-stage drug discovery projects within the pharmaceutical industry.

• Realising our £50m commitment to the UK Dementia Research Institute, as part of a £290m investment from the UK government and Alzheimer's Society, to create a world-leading hub for dementia research.

• Investing £36m into the second phase of the Alzheimer's Research UK Drug Discovery Alliance, a network of Drug Discovery Institutes housed in world-leading academic centres in the UK to focus on translating promising scientific breakthroughs into the clinic.

• Introducing a Target Robustness Programme to facilitate the translation of new discoveries into early-stage drug discovery.

• Leading the Dementia Access Taskforce to ensure that when new treatments are available people with dementia can access them as soon as possible.

• Significantly growing the portfolio of Alzheimer's Research UK-funded preclinical and clinical research, partnering with other funders when appropriate.

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