The power to defeat dementia

Manifesto 2015 - 2020
Over 850,000 people, or an average of 1,500 people in each constituency, are living with dementia.

Dementia is a medical condition, like cancer or heart disease, not just a natural part of ageing.

For every £1 spent on dementia research around £7 is spent on cancer research.

Dementia kills. According to the office for National Statistics, it is the leading cause of death for women and the third biggest killer of men.

Dementia is the most feared condition amongst those over 55.
Defeat Dementia –
Alzheimer’s Research UK’s action plan for government

DEFEATING DEMENTIA WILL BE HARD. It will require an effort equivalent to putting man on the moon. Research is the only way to defeat dementia.

Alzheimer’s Research UK is the leading dementia research charity in Europe. Every day we are in touch with people living with dementia, their families and carers, and they tell us how vital our work is and what finding a cure would mean to so many lives.

We are committed to funding the highest quality research to improve the lives of people with dementia and ultimately defeat the condition. That is why we have launched Defeat Dementia, our new campaign to raise £100 million over 5 years.

This campaign will make a huge difference, but we will not defeat dementia on our own. Organisations and governments across the globe need to come together and share a vision of a world free from dementia. The UK is in a strong position to be the leader in overcoming the challenges to defeat dementia.

WE HAVE IDENTIFIED FIVE KEY STEPS WHICH WOULD SEE THE UK TAKE THE LEAD IN DEFEATING DEMENTIA:

1. **INCREASE RESEARCH FUNDING.** Dementia research is underfunded compared to the amounts committed to other conditions. This has to stop and all nations could do more - the UK should take the lead by committing to double funding every five years until 2025.

2. **INCREASE RESEARCH CAPACITY.** We need more of the best scientists working in this field. Alzheimer’s Research UK wants to see 50% more neurodegeneration researchers by 2020. ARUK will be doing our bit and funding nearly half of these - government and industry should commit to match us.

3. **REMOVE REGULATORY BARRIERS.** We want the UK to lead an international collaboration to streamline regulation across international borders and reflect the lengthier R&D process for dementia medicines in intellectual property laws.

4. **DEVELOP BETTER TREATMENTS FASTER.** Great ideas that never make it off the lab bench are pointless. The UK has the opportunity to be the best environment in the world, if government investment is made in research infrastructure that supports our universities to translate research in treatments for patients.

5. **IMPROVE THE LIVES OF PEOPLE LIVING WITH DEMENTIA.** Our research is increasingly revealing the causes of dementia and the steps that can be taken to prevent or slow its advance. Investing in evidence-based public health measures can have an impact right now.
Alzheimer’s Research UK has pledged £100 million for dementia research in our new five year campaign – Defeat Dementia. The campaign aims to grow the research field and accelerate progress towards new treatments. It represents the largest ever UK charity commitment to dementia research and will see a £100 million investment across initiatives covering diagnosis, prevention and treatment of Alzheimer’s and other dementias. Pledges as part of ‘Defeat Dementia’ include:

• The Alzheimer’s Research UK Stem Cell Research Centre – a £2 million collaborative venture between researchers at the Gurdon Institute at the University of Cambridge and University College London to understand the causes of Alzheimer’s and screen potential new treatments.

• A network of Drug Discovery Institutes, funded at £30 million, housed in academic centres in the UK to allow promising breakthroughs to be translated towards the clinic.

• A £20 million Global Clinical Development Fund dedicated to supporting phase I and II clinical trials to take potential new treatments into testing in people as soon as possible.

This will make a huge difference, but we will not defeat dementia on our own. Our campaign will focus on catalysing change by leveraging investment from other global funders, but in order to defeat dementia we need to ensure that governments and the international community share our vision. We must harness the promising international momentum created by the formation of the World Dementia Council and Global Dementia Innovation Envoy and provide solutions to the challenges that need to be overcome to defeat dementia.

Research is the only way to defeat dementia.

“My dear mum is my inspiration for running. Every marathon I complete is a tribute to her. Having watched her fade away with vascular dementia, I’m determined to do everything I can to raise money and awareness for the research experts, Alzheimer’s Research UK.’

Susie Hewer, Sussex
Defeat Dementia –
Action plan for Government

Research is at the heart of what we do at Alzheimer’s Research UK. We have identified five key steps to successfully defeat dementia:

1. **Increase Research Funding**

2. **Increase Research Capacity**

3. **Remove Regulatory Barriers**

4. **Develop Better Treatments Faster**

5. **Improve the Lives of Those Living with Dementia**
As well as the devastating human cost, dementia costs the UK economy £24 billion per year, which is estimated to be significantly more than cancer, stroke or heart disease. The current Government and other G7 leaders have pledged to find a cure or disease-modifying treatment by 2025. This is a very welcome, ambitious target but currently the scale of funding does not match this ambition. Dementia research has historically been underfunded compared to other major disease areas.

Research investment must focus on targeting funds at the most promising research.

At Alzheimer’s Research UK we have set out our £100 million campaign to meet the challenge over the next 5 years. We believe a realistic aim for the UK government is a further doubling of funding from 2015, every 5 years through to 2025. This would take spending from £66 million in 2015 to £132 million by 2020 and £264 million by 2025.

Funding for dementia research should be part of a broader commitment to increase investment in life sciences.

The Science and Research Funding budget is over £4.5 billion per year and the main UK research councils receive over £2.5 billion each year. We need to ensure more funding is available to be allocated to the highest quality, innovative ideas in dementia research. The Allocation of Science and Research Funding will be renewed in 2015 and the UK is currently one of the few EU countries not committing to a target of 3% of GDP spent on Research and Development (R&D) by 2020. In 2012 the UK spent 1.72% of GDP on R&D. The new Allocation should aim to achieve 3% of GDP by the end of the next parliament in 2020.

The Charity Research Support Fund (CRSF) leverages charitable investment by allowing higher education institutions (HEIs) to apply for overhead costs that are so vital to the university to support the research being funded. This fund has remained flat for the past 3 years, while charitable
investment has significantly increased. If the government is to successfully leverage investment from charities and ensure quality infrastructure in HEIs in place to support our research, the CRSF must increase in proportion to increases in charitable investment.

Support for the UK’s life sciences sector and dementia research infrastructure will be a key contributor to sustained economic growth. Research has a positive impact on GDP and with the right investment dementia is potentially the next big growth area. Every £1 increase in public funding for medical research generates up to £5 of investment into research by the pharmaceutical industry. In the UK, the pharmaceutical industry employs 165,000 people, and invests approximately £11.3 million per day (nearly £4.2 billion per year) in research and development. We need to do more to ensure a greater proportion of this investment is channelled into dementia research. A report by the Health Economic Research Group at Brunel, Office for Health Economics and RAND in 2008 found that the rate of return of public / charitable research investment from GDP gains is ~30%. While the analysis focused on all types of medical research, it gives an indication of the return on investment that could be generated by a large increase in funding for dementia research.

By investing in research and innovation that will tackle the big societal challenges governments can act as a leader and catalyst for future private investment. This is an important leadership role for governments – it will drive future co-investment between public funders and more risk-averse private investors in important societal challenges, including finding a cure for dementia. The UK government currently has a unique opportunity to demonstrate this leadership on a global scale and work collaboratively with the international community to develop ways to incentivise further investment.

What we would like to see from government

- A doubling of funding on dementia research by 2020 from £66 million in 2015 to at least £132 million by 2020.
- A commitment to dementia research should be part of a commitment to an ambitious target of increasing funding for scientific research in the UK to 3% of GDP.
- The Charity Research Support Fund (CRSF) must increase in proportion to charitable investment in higher education institutions.
- The welcomed above-inflation increases in capital investment up until 2021 must be maintained and aligned to support key research priorities, of which dementia should be one.
- The government must encourage innovative solutions to raise private investment and ensure the recommendations of the World Dementia Council are taken forward.
- Continued commitment to Research and Development (R&D) Relief for Corporation Tax at current levels.

What would good progress look like by 2020?

- Over £130 million invested each year by government in the highest quality dementia research and 3% GDP invested in R&D in the UK.
- A global investment fund for dementia research, with innovative new investment models.
- A tax incentive scheme that encourages investment into companies who are making an operational loss while developing new therapies.
- UK charitable investment of over £30 million per year in the highest-quality dementia research.

3 ONS (2013), ‘UK Business Enterprise Research and Development’
4 HeRG, OHe, RAND (2008) Medical Research: What’s it worth? estimating the economic benefits from medical research in the UK. Medical Research Council, the Wellcome Trust and the Academy of Medical Sciences
The quality of dementia research, and therefore the prospects of finding a disease-modifying therapy by 2025, is dependent on the numbers of excellent people doing the research. This is why it is crucial that increases in investment are translated through to a proportional increase in the number of researchers in the UK.

Alzheimer’s Research UK’s investment over the next 5 years aims to deliver a 20% increase in the number of dementia researchers in the UK, but with additional spending from government and other private and philanthropic investors there should be an overall ambition for a 50% increase. This would create an additional 1500 – 2000 researchers working in the neurodegeneration field, from 3600 today to over 5000 by 2020. The Global Action Against Dementia initiative, led by the UK, could help to increase those numbers as well.

If we are to strengthen clinical research and make the NHS the best place in the world to do research then we need to create a stronger research culture in the NHS.

NHS England has set out its vision that ‘research is everyone’s business’ and more needs to be done to make this happen. There needs to be both support for staff to help them promote participation in dementia research and clinical trials, and also the right incentives and career development pathway in place to encourage more clinicians to develop research themselves.

What we would like to see from government

- Government funding of specific grants for PhDs in neurodegeneration and early career support for dementia researchers that also encourages them to stay in the field.
- Government funding for interdisciplinary grant schemes to attract established researchers into the field.
- Capital funding for dedicated dementia research centres and continued investment to upgrade equipment and facilities to the highest standards.
- More incentives to take part in research through NHS employment contracts and professional development opportunities.
- Opportunities for people with dementia to participate in research integrated into care pathways across the NHS, building on the work of Join Dementia Research.
‘Watching Jamie slowly deteriorate in front of me is incredibly painful. We have to face what’s happened and we’ve made it our mission to do everything we can to help Alzheimer’s Research UK. More scientists and support for their work are desperately needed to make strides towards defeating dementia.’

Vicki Graham, Wiltshire

What would good progress look like by 2020?

- 50% more researchers working in the field of neurodegeneration, an increase from around 3,600 today to around 5,400 in 2020².

- Talented researchers from other disciplines applying their knowledge and skills to neurodegenerative research.

- Over 10% of people with dementia involved in research.
Increasing investment will only make a difference if we can get drugs to patients sooner. However, currently there are a number of regulatory barriers that are preventing optimum conditions for research into dementia, this includes:

- The time it takes to get regulatory approval for clinical trials.
- The limitations of current intellectual property and data exclusivity regulation – they do not sufficiently take into account the additional length of time it takes to develop dementia drugs.

We would like to see government explore these barriers and ensure regulatory bodies streamline processes that hinder investment in dementia research. **We would like to see commitment from government to work with regulatory authorities, both domestically and internationally, to agree new avenues to encourage investment in drug discovery.** Agreements to afford more generous licensing and exclusivity could be made alongside a commitment for increased investment from the pharmaceutical industry that reflects the potential returns in a new more competitive regulatory environment. This type of agreement would generate significant amounts of new investment into dementia research and increase the likelihood of finding a cure or disease modifying treatment.

Once potential drugs are developed into the clinical phase, it will be crucial to have the engagement of the NHS to support participation in clinical trials. The inability to recruit appropriate people into research at the right time in the progression of their condition is one of the reasons why clinical trials could fail. When promising treatments do reach clinical development, a ‘trial-ready’ cohort of people ready to take part in research will speed up the drug development process. Working with the National Institute for Health Research (NIHR) we are part of Join Dementia Research, an initiative to identify individuals who are interested in participating in dementia research and can form a ‘trial-ready cohort’.

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**What we would like to see from government**

- A commitment to work with the MHRA, EMA, FDA and regulators in other parts of the world to develop a more appropriate regulatory pathway for dementia research that will encourage renewed investment.
- Reduced thresholds for efficacy data in clinical trials based on the challenges of identifying suitable candidates for treatment specific to dementia.
- Regulatory incentives such as waivers or fee reductions for drug development companies or partnerships working in the field.
- Priority consideration for regulatory approval of dementia treatments to significantly reduce the amount of time it takes to review a product and move it to market.
- Continued development and expansion of EMA-FDA joint regulatory pathways that simplify the approval process.
- A reduction in the threshold for moving between clinical trial phases or a conditional approval scheme for treatments showing possible improvements in small trials.
- The continued development of the Early Access to Medicines Scheme, with a straightforward pathway to approval and strong communication between MHRA and NHS England.
What would good progress look like by 2020?

- An international agreement to adopt regulatory incentive(s) that will stimulate greater investment in dementia research.

- A corresponding significant increase in investment from the pharmaceutical industry and biotech companies.

- A series of ‘trial-ready’ sites across the UK, where research to test new treatments can begin rapidly.

- Trial-ready cohorts of people to take part in dementia research recruited through a thriving Join Dementia Research programme.

- A significant reduction in the time it takes to secure clinical trial approval.

- 10% of people diagnosed with dementia involved in research.
The translation of fundamental academic science into patient benefit, accelerating research from bench to bedside, is a critical component of success.

It is the nature of scientific research that it is impossible to know in advance what findings will prove to have a practical utility. The process of translation is where novel findings are replicated and investigated for their potential to provides new drug targets, new model systems that can be used to mimic disease processes, and new ways to assess disease progression in patients. Historically, much of this work has been performed by the biotech and pharmaceutical industry, but their involvement in dementia research is being reduced worldwide due to commercial pressure and a better prospect of receiving a return on investment in other disease areas, such as cancer, inflammation and diabetes. This is leaving a ‘translational gap’. To close this gap and speed up the development of new drugs, Alzheimer’s Research UK is developing a series of Drug Discovery Institutes (DDIs) as a new model of collaboration.

They will provide the essential link between fundamental research and drug development for neurodegenerative diseases.

We have also founded The Alzheimer’s Research UK Stem Cell Research Centre, and the Dementia Consortium, which solicit new drug targets worldwide for early translational research. Without these activities, the flow of new, innovative ways to treat neurodegenerative diseases will dry up.

For collaborative initiatives to be effective there must be support for knowledge-sharing among research partners that allows for the exchange of data while protecting intellectual property and the privacy of individuals.

Data sharing maximises the potential benefit of such partnerships and builds upon promising work. The facilitation by the NHS for access to patient records of those who elect to participate in research, as well as anonymized data, could lead to leaps in scientific knowledge about the diseases that cause dementia. Initiatives such as care.data provide critical links to information that is otherwise inaccessible and has the potential to dramatically improve knowledge of the condition.

What we would like to see from government

• Infrastructure support and investment for those academic institutions that are participating in the DDI framework.
• Encouragement for the funders to provide additional grants for drug discovery projects to support the DDIs.
• A data sharing arrangement for promptly making pre-competitive data public to maximise the potential benefit. This should build on existing efforts such as the UK Dementia Platform (UKDP), Global Alzheimer’s Platform (GAP) and the Innovative Medicines Initiative (IMI EPOC-AD) that are all attempting to speed the field toward treatments by helping pharmaceutical companies share resources in the early phases of drug testing. A successful example of this is the ‘Bermuda Principle’ employed for the Human Genome Project.
• Accessible anonymized NHS data for research purposes through the implementation of care.data with opt-out consent for patients. Communication and explanation of the value and governance is crucial and medical research charities could help in communicating the benefits.
• Speeding up the time it takes to get regulatory approval to start a clinical study through support for fast-start clinical trials and standing cohorts for dementia research.
What would good progress look like by 2020?

- Capital investment in place to support Drug Discovery Institutes working to get treatments to patients faster.
- A network of academic-based Drug Discovery Institutes in the UK linked to partners across the globe. They will have a portfolio of potential treatments in the pipeline, a number of which will be close to clinical trials.
- Increased pharmaceutical investment in dementia research, both in the UK and globally, to reflect the steps taken to create a more favourable market.
- An Early Access to Medicines Scheme that is working seamlessly between MHRA and NHS England and ready to act efficiently to make potential dementia treatments available.
- Participation by UK funders in the International Alzheimer’s Disease Research Portfolio (IDRAP) – to share data and findings.
- A data sharing agreement and platform across industry and the research community to share pre-competitive data.
Dementia can destroy lives, not only of those living with the disease but the families and carers around them. While we continue to work towards effective treatments, we need to do more to prevent the condition and improve the lives of people living with the symptoms.

There is a growing body of research that shows a link between certain risk factors (mainly the key cardiovascular risk factors) and dementia. Current evidence suggests that a third of cases of Alzheimer’s disease could be prevented by mitigating seven key risk factors, such as physical inactivity or smoking. Lifestyle and general health factors such as these may have an impact on general brain health and in the instances where dementia does occur, the same lifestyle choices may help to mitigate co-morbidities and improve quality of life. We would like to see more public health messaging include dementia and more proactive initiatives to reduce the potential risk and promote a healthy lifestyle. We also need more research into the causal mechanisms that link specific risk factors to development of Alzheimer’s disease and other dementias so that we can improve the targeting of interventions in the future.

While the only way to truly defeat dementia is to find an effective prevention or treatment, it is important that people who are living with the condition are given the best possible support. Innovation in technology is key to supporting people and potentially helping delay the progression of their condition. For example, digital tools may eventually help people to retain memory and live independently for longer. We encourage government support for more research into these promising areas.

What we would like to see from government

- An emphasis on helping people to reduce the risk of developing dementia. A programme of work that integrates awareness of dementia risk factors with other interrelated disease areas such as heart disease and diabetes.
- A government-led effort to reduce the stigma of dementia by supporting people living with dementia to access accurate information about their condition. This should be in conjunction with charities that provide information like Alzheimer’s Research UK.
- A commitment by the government to address both regulatory and economic barriers to accessing treatments when they become available.
- The inclusion of dementia awareness in policies governing the built environment.
- Patient access to their own data allowing better benchmarking for their condition and providing a better explanation of what results mean.
‘I’m delighted to see the government and the world putting dementia investment on the agenda, but it’s up to all of us to play our part in making it a thing of the past. Alzheimer’s Research UK has the expertise, and ‘Defeat Dementia’ shows a whole new level of ambition to help make possible for dementia the kind of wondrous breakthroughs that are making such a difference for people with cancer and heart disease.”

Carol Franklin-Adams, from Surrey

What would good progress look like by 2020?

- A public health campaign which breaks down the stigma that surrounds dementia and also explains the potential preventative measures that could cut individuals’ risk of developing dementia. It would also explain the research effort to discover a disease-modifying treatment, giving people living with dementia hope.

- Dementia-friendly communities continue to grow and levels of public awareness about the disease match that of cancer.

- A culture of patient ownership of their health records and an understanding of how these data might, and might not be, used for research purposes.

- The use of evidence-based interventions targeted to reduce the main risk factors associated with dementia.
Alzheimer’s Research UK: the UK’s leading charity specialising in finding preventions, treatments and a cure for dementia.

To find our more, or discuss the document in more detail contact Dr Matt Norton, Head of Policy and Public Affairs on 01223 824575 / m.norton@alzheimersresearchuk.org