Agenda 2030: One Nation Labour’s Plan for science
Response from Alzheimer’s Research UK

1. Introduction

1.1. Alzheimer’s Research UK is the UK’s leading dementia research charity. As research experts, we specialise in funding world-class, pioneering projects at leading universities to find preventions, treatments and a cure for dementia. We believe science and innovation hold the key to defeating dementia and invest in the scientists discovering more about the condition and its causes.

1.2. Alzheimer’s Research UK is funded almost entirely by public donations and through the generosity and support of all the trusts, companies and individuals that support us, in 2013 we increased our income by an impressive 21 per cent to £11,037,304. We have also launched the biggest fundraising campaign in UK dementia research history, aiming to raise a minimum of £100 million over the next 5 years.

1.3. We welcome the opportunity to comment on this Green Paper for science and look forward to engaging with the proposals on an ongoing basis. Alzheimer’s Research UK has extensive experience in driving innovation in dementia research and life sciences more broadly and we would welcome an opportunity to meet with Rt. Hon Liam Byrne to discuss our work. We also look forward to meeting the Shadow Health Team at the Labour Party Conference at an event co-hosted with the Fabian Society, to discuss dementia research.

1.4. Below we outline our response to some of the key areas of the Green Paper and also share our insight into what we think a successful strategy for science should include.

2. Executive summary

2.1. We support Labour’s focus on long-term planning and investment for science and research and charities should be a key stakeholder in developing these plans. Charities hold a wealth of knowledge and understanding in the sector and can offer expert neutral advice on long-term priorities. We have also invested heavily in establishing broad international links that can significantly support the development of priorities, and the solutions to those priorities, that can have an impact at a much a larger scale.

2.2. Alzheimer’s Research UK’s recommendations include:

2.2.1. There needs to be a long-term plan and sustained investment for science and the necessary infrastructure to support research, with charities engaged as a key stakeholder in developing the strategy. In terms of medical research, planning should reflect the full cycle of innovation – from investing in ideas to delivering treatments to patients as quickly as possible.

2.2.2. Public funding should be used as a catalyst for private investment and leverage funding from different sectors, including charities and industry – the evidence suggests that
this is the best way to leverage maximum investment. This should be done in the most effective way to maximise the impact of existing and future funding, for example the CRSF should be sufficiently funded to best leverage funding from charities.

2.2.3. Dementia should be seen as a ‘grand challenge’ and dementia research made a priority area for increased investment. We should also maximise the UK’s opportunity to become a global innovation hub for dementia research as this would be strategically advantageous to the UK and could attract funding and research talent.

2.2.4. In terms of medical research specifically, we want to see a commitment from governments to work with the regulatory authorities, both nationally and internationally, to encourage investment in drug discovery. We are also calling for the length of time it takes to get approval for clinical trials to be reduced and better access to patient data that researchers need to find effective treatments.

2.2.5. We should make the NHS the place to do clinical research and strengthen the research culture in the NHS to encourage more patients to take part in clinical trials and increase capacity in research through encouraging more clinicians to lead research.

3. Making the case for science being at the heart of policy making – investing in science and research for the benefit of society and the economy

3.1. There is a compelling case to invest in science and research, it not only has the potential to improve people’s lives through finding new treatments and cures for diseases, it is also a key contributor to economic growth in the UK and has a positive impact on GDP. For example, 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 per cent.¹

3.2. In addition, Cancer Research UK, the Department of Health, the Academy of Medical Sciences and the Wellcome Trust have recently commissioned research into the economic return of public and charitable investment in cancer research.² The report concludes that for every charity and taxpayer £1 invested into cancer-related research, there is a return of 40p to the UK every year. They estimate that 30p of this is the ‘spillover’ effect from research to the wider economy, whilst 10p reflects the monetised health benefits.

3.3. We agree that this investment should not just focus on investing in ideas, but should also focus on the infrastructure needed to ‘take innovative ideas from the lab and the classroom to the market place’. Alzheimer’s Research UK is committed to this and is currently looking to invest in Drug Discovery Institutes as a way of working with universities, NHS hospitals and industry to develop and deliver drugs to patients as quickly as possible. Our model for

¹ 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
drug discovery is driven out of institutes being more closely linked to academic institutions and 
we would be very pleased to talk to Rt. Hon Liam Byrne MP about these.

3.4. We would be interested to learn more about the concept of a British Investment Bank. We
need to develop new and innovative funding mechanisms to drive investment in areas such
as dementia research and we would be keen to discuss current thinking about how to
achieve this. We are currently involved in a number of programmes of work focusing on
creating investment funds for dementia research and we would be delighted to discuss how
the principles being developed for dementia could be transferred to the broader life
sciences.

4. Increasing and leveraging investment from other sectors

4.1. We welcome a focus on using public investment to drive greater private investment.
Governments can show leadership and act as a catalyst for others to invest in research that
significantly benefits society. For example, every £1 increase in public funding for medical
research generates up to £5 of investment into research by the pharmaceutical industry.3 In
the UK, the pharmaceutical industry employs 165,000 people and invests approximately
£11.5 million per day (nearly £4.2 billion per year4) in research and development.

4.2. Government funding in science can also importantly leverage investment from other
sectors, including the investment from charities and industry. For example, the
Government’s support for the Charity Research Support Fund (CRSF) is an excellent
measure to leverage the investment charities have made in Higher Education Institutions
(HEIs). Whilst we wholeheartedly support the CRSF, we are concerned its funding has
remained flat at £198 million since 2010/11. This could potentially result in a deterioration
of infrastructure that supports charity funded research in HEIs and not effectively leverage
this investment to its full potential.

5. Investing in dementia as one of the greatest challenges of our generation

5.1. Focusing on what the plan describes as ‘grand challenges’ would help ensure that
investment is channelled into areas that will make the biggest difference to society.
Dementia is one of the greatest challenges of our generation and we want to see a greater
allocation of science and research funding to dementia research, including greater
investment in the infrastructure through capital spending to support the development of
the best ideas.

5.2. Whilst vital discoveries are being made all the time, there are currently no effective
treatments or a cure for dementia and this needs to change.

5.3. Key information about dementia:

3 Alzheimer’s Research Trust (2009), ‘Forward together. Complementarity of public and charitable research with respect to private spending’
4 ONS (2013), ‘UK Business Enterprise Research and Development’
5.3.1. Over 800,000 people are affected by dementia across the UK and 44 million people across the world.

5.3.2. The annual cost of dementia in the UK is £23.6bn, this rises to £360bn worldwide. By 2030, with an ageing population, the costs will rise by a further 85 per cent, with much of the cost being met by unpaid carers including families.5

5.3.3. 1 in 3 people over 65 will die with some form of dementia.6

5.3.4. There are currently an estimated 705,000 family carers of people with dementia in the UK.7

5.3.5. 7.3 million people over 55, 41 per cent of those over 55, rank dementia as the biggest medical challenge today, it is also the most feared condition amongst those over 55 years.

6. The impact of investing in dementia research

6.1. With the right investment, we believe dementia is potentially the next big growth area and has the potential to strengthen investment in the UK. For example we have an ambition to structure our Drug Discovery Institutes so they are networked at an international level, with the UK acting as the research leader. Our Drug Discovery Institutes are an example of where greater investment could have a large scale impact for people and also position the UK as a global hub for drug development for dementia. This would be strategically advantageous to the UK and could attract both funding and research talent.

6.2. Working with the Office of Health Economics, we have also developed an economic model to examine the impact of hypothetical disease modifying treatments. Analysis published in our recent report ‘Defeat Dementia’ shows that the numbers of people with dementia in the UK are set to grow rapidly over the next 36 years from around 831,000 people today to 1,133,000 in 2025 and 2,014,000 by 2050. However, if by 2020 a treatment was developed that could delay the onset of dementia by 5 years, there could be:

6.2.1. Thirty-six per cent fewer (469,220) people with dementia by 2030 and hence 398,837 fewer informal carers required. The reduction in numbers of people with the condition would mean dementia would cost £14.1 billion less in 2030 than without a treatment.

6.2.2. 666,000 fewer people with dementia by 2050 and 566,000 fewer informal carers required. The reduction in numbers of people with the condition would mean dementia would cost £21.2 billion less in 2050 than without a treatment. Thus an intervention that delays the onset of dementia by five years could reduce costs by 36 per cent in 2050.

---

5 Alzheimer’s Research UK (2014) ‘Defeat Dementia – the evidence and a vision for action’
7 Alzheimer’s Research UK (2014) ‘Defeat Dementia – the evidence and a vision for action’
8 YouGov polling, December 2013 and population estimates from ONS, 2013
7. **Strengthening collaboration and a joined up approach**

7.1. Policy makers should ensure there is an environment that facilitates collaboration at an international level and across the research community. Working collaboratively across governments, different government departments, universities, the NHS, local communities, the pharmaceutical industry and independent charities will help ensure we deliver important changes for people and our economy.

7.2. We support Labour’s focus on international collaboration in this plan. Dementia research is an excellent example of where international collaboration and leadership is already happening and where there is significant momentum to build on. The commitment of the G7 nations to work together to improve dementia research has had a significant impact on building international relationships and a shared sense of ambition to defeat dementia. This is essential if we are going to tackle it on a global scale.

7.3. In December last year the World Dementia Council was established and has responsibility for taking forward the initiatives of [Global action against dementia](#). The UK has a leadership role in driving dementia research and has an opportunity to become a global innovation hub for dementia research.

7.4. There also needs to be an environment that facilitates collaboration across the different sectors at a national level. If we are going to find new treatments for people with dementia there will need to be effective collaboration across universities, industry, the NHS and charities. For example, we strongly believe that drug discovery is not just the role of industry and the breakthrough for some will be achieved through bringing SMEs, academics and pharma together in collaboration and our Drug Discovery Institutes will bring together basic science and clinical expertise together with drug discovery. We have also launched our Dementia Consortium which is a collaboration between Alzheimer’s Research UK, the MRC and two pharmaceutical companies Eisai and Lilly (see case study on Pg. 6)

7.5. We also want to see improved linkages and collaboration between government departments in order to deliver an effective science strategy. There are a great deal of inter-dependencies between different departments, especially between the Department of Health and the Department for Business, Innovation and Skills, and it is important that opportunities to work more closely together are realised.

7.6. We support the notion that we need to increase research strength across the country, recognising a great deal is happening within the South East. To help facilitate and develop regional research strength we currently run a network of 15 research centres across the country and we would be delighted to talk to you about how this works in more detail.
CASE STUDY: Alzheimer’s Research UK’s Dementia consortium

We have launched a new Dementia Consortium which is an example of collaborative working across different parts of the research community. It will fund leading academic dementia research experts from the UK and overseas to develop early findings into validated drug targets for Alzheimer’s and other dementias.

The Dementia Consortium provides funding, resources and expertise to both increase the number of, and capitalise upon, new drug targets emerging from across the academic sector that hold promise of bringing patient benefit.

The Dementia Consortium members are Alzheimer’s Research UK, technology transfer and drug discovery experts MRC Technology and two pharmaceutical companies; Eisai and Lilly and has made £3m available (£2m from Alzheimer’s Research UK and £500k from both Eisai and Lilly) for its first three years.

8. Creating a supportive regulatory system

8.1. Policy makers should have a focus on working with the regulators to create a supportive regulatory system. There are currently a number of regulatory barriers that are preventing optimum conditions for research into dementia, including the time it takes to get regulatory approval for clinical trials and the prohibitive nature of intellectual property and data exclusivity because of the additional length of time it takes to develop dementia drugs.

8.2. It is also important that the regulatory environment supports the use of patient data in medical research. Whilst we completely understand that strong safeguards need to be in place to protect people’s personal information, data sets play an essential role in furthering medical research. There needs to be a focus on ensuring that European Data Protection Regulation does not have the unintended consequence of limiting access to important data needed for research.

9. Linking science with the NHS

9.1. We strongly believe that long-term planning and investment for science should align with the priorities for patients and the NHS, which is why we want to see greater investment in dementia research.

9.2. We can also make optimal use of the NHS to set the gold standard for conducting clinical research. The NHS has the potential to be a world leader in clinical trials and research and it is important to break down barriers around data and integrated working that would allow the NHS to thrive as a research hub. Much of the infrastructure is in place, it needs joining...
up and the removal of key barriers – such as incompatible IT systems and prohibitive data governance.

9.3. The research culture in the NHS should also be strengthened. For example providing greater support for staff so they are better equipped to talk to patients about different clinical trials they can get involved with, and also incentivising more clinicians to enter research as part of their career development and progression.

10. Conclusion

10.1. There is a compelling social and economic case to invest in science and the grand challenges that would greatly benefit from increased focus and investment, dementia is one of these challenges. Creating an environment that supports a more joined-up approach is important if we are going to address significant global challenges and make the most of existing and new resources.

11. Contact

11.1. If you have any questions relating to this response, or dementia research more generally, please contact Clare van Lynden, Policy and Public Affairs Advisor, c.vanlynden@alzheimersresearchuk.org or on 01223 824580.