Alzheimer’s Research UK response to the Department of Health and Social Care Major Conditions Strategy call for evidence

Introduction

In January 2023 the UK government announced its plan to publish a Major Conditions Strategy. Interventions set out in the Strategy will aim to alleviate pressure on the health system, as well as support the government’s objective to increase healthy life expectancy.

In May 2023, the government launched a call for evidence to inform the Strategy. The call for evidence sought views on how best to prevent, diagnose treat and manage six major groups of conditions, specifically: cancers; cardiovascular diseases, including stroke and diabetes; chronic respiratory diseases; dementia; mental ill health and; musculoskeletal disorders.

Below we set out Alzheimer’s Research UK’s response to the call for evidence. There were four specific questions of relevance. Any questions about the response should be emailed to policy@alzheimersresearchuk.org.

1. How can we support people to tackle preventable risk factors?
   a. Prioritising brain health for dementia risk reduction
   • With no treatments currently available in the UK that can stop the diseases that cause dementia, we need government action to promote brain health throughout life.
   • The concept of brain health resonates with the public: only a third of UK adults (33%) realise there are steps they can take to reduce their dementia risk, compared to 75% who believe they can influence their brain health.¹
   • 40% of dementia cases globally could potentially be prevented by addressing socioeconomic and lifestyle factors that negatively affect our brain.² Risk factors for dementia are shared with other major diseases such as cardiovascular disease and cancer including physical inactivity and smoking – contributing to the high burden of preventable ill-health.³
   • Optimising brain health within the population has clear social and economic benefits.⁴ Prioritising brain health would also reduce health inequities and provide cost savings to the economy, for example in social care: the total cost of care for people with dementia in the UK in 2019 was £34.7bn.⁵

b. The need for a range of policy interventions
   Population level-interventions
   • The Strategy should promote lifelong brain health via a range of policy interventions co-ordinated by relevant government departments. This must include population-level interventions that tackle the breadth of risk factors and wider determinants of health that individuals have little control over, such as air pollution. Population-wide interventions

¹ Alzheimer’s Research UK, Dementia Attitudes Monitor: Wave 2 report 2021
offer the most equitable and cost-effective means of improving the nation's brain health.\textsuperscript{6 7}
\textsuperscript{6} These should include:
\begin{itemize}
  \item ambitious targets to reduce air pollution
  \item greater investment in incentivising public and active travel over motor vehicles
  \item interventions that reduce the affordability of foods high in fat, sugar or salt
  \item reducing the affordability of tobacco (a key recommendation of the Khan Review\textsuperscript{8}).
\end{itemize}
\textsuperscript{8}
\item These interventions need to be part of a wider government commitment to tackle health inequalities and narrow the gap in healthy life expectancy between the poorest and richest. As not only does deprivation increase exposure to known risk factors for dementia but research indicates deprivation itself is damaging to brain health.\textsuperscript{10}

\section*{Individual level interventions}
\textsuperscript{10}
\item Targeted individual level interventions also have a role to play for example:
\begin{itemize}
  \item Nicotine replacement therapy, provision of hearing aids and treatment for high blood pressure, if fully implemented, could reduce dementia prevalence by 8.5%, providing quality of life benefits to individuals and saving more than £1.83bn annually in England.\textsuperscript{11}
  \item The NHS Health Check should be transformed into a more holistic tool to better identify at-risk individuals and enable people to take preventative action. This aligns with the remit of Professor Deanfield’s Personalised Prevention Taskforce. Personalising the NHS Health Check should also include simple additions like a hearing check to identify mid-life hearing loss.\textsuperscript{12}
  \item A national roll-out of Brain Health Clinics\textsuperscript{13} would ensure that those identified at higher risk by the NHS Health Check can get tailored personalised support.
  \item The government should also consider scaling up public information campaigns that empower people to protect their brain throughout life such as ARUK’s Think Brain Health initiative.\textsuperscript{14}
\end{itemize}

\section*{2. How can we better support local areas to diagnose more people at an earlier stage?}
\subsection*{a. Address diagnosis disparities}
\item Dementia diagnosis rates in England for individuals over 65 currently stand at just 63%, leaving over a third of people with dementia undiagnosed. However, there is significant local variation: the diagnosis rate in Herefordshire and Worcestershire is 53%, compared to 73% in South Yorkshire.\textsuperscript{15} It is imperative to address these disparities to ensure equitable access to diagnosis and subsequent care. To achieve this, the Major Conditions Strategy should:
\begin{itemize}
  \item Mandate routine data publication, like the Memory Assessment Services Audit, that covers all health care settings performing dementia diagnoses.
  \item Publish national and local-level data on people’s age at diagnosis, underlying causes of dementia (disease subtype) and demographic factors such as gender, ethnicity, socioeconomic background and educational attainment.
\end{itemize}
\textsuperscript{15}

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“We would not accept you have ‘cancer’ as a diagnosis. Nor would we accept random radiotherapy for cancer without knowing what we were trying to cure, so why is it expected that we will with dementia?” (Policy Insight & Experience Panel Member).

b. Improve access to specialised diagnostics
   • Diagnosing the cause of dementia, such as Alzheimer’s or vascular disease, significantly impacts care and treatment plans. However, access to specialised diagnostics like PET scans and lumbar punctures remains severely limited: only 2% of people can access them on the NHS.\textsuperscript{16} Scaling up provision of PET scans would cost the NHS an estimated £3bn over ten years because of largescale infrastructure requirements, costs and need for a specialist workforce.\textsuperscript{17} Scaling up access to lumbar punctures is more feasible. To support the arrival of new treatments, we recommend the following actions to go from delivering just 2,000 currently to 20,000 lumbar punctures a year:
     - Invest an initial £16m in infrastructure, equipment, and workforce training, including 50 new band 6/7 nurses or equivalent across the UK regions.
     - Commit to sustained annual investment of £10m for such services until new diagnostic tools can replace lumbar punctures.

c. Redesign the clinical pathway
   • Dementia diagnosis and treatment pathways have seen limited innovation over the past two decades. It is vital to adapt these pathways to align with new medical advances, such as the emergence of disease-modifying treatments. To achieve this, we recommend the following steps:
     - Work with the clinical community and the NHS to develop and implement a new clinical pathway for Alzheimer’s disease.
     - Support and invest in the roll-out of a network of Brain Health Clinics to deliver equitable, high-quality service across the UK. These should be commissioned by NHS Integrated Care Boards to ensure they meet local needs.

d. Embrace innovative diagnostics
   • Significant progress has been made in developing cheaper, scalable, and accessible tools for dementia diagnosis. For instance, blood tests for dementia are rapidly evolving and have already shown promise in other countries. To capitalize on these advancements, the Major Conditions Strategy should:
     - Invest via the NHS in a national clinical trial of blood tests for dementia across existing Brain Health Clinics.
     - Support work to implement other innovative diagnostics such as digital cognitive tests and ultra-rapid MRI to increase scanner capacity.

3. How can we better support and provide treatment for people after a diagnosis?
   • Recent progress in disease-modifying treatments (DMTs) for dementia offers hope, with promising therapies targeting the underlying causes and ongoing clinical trials fuelling optimism for future breakthroughs.

   • Two DMTs for Alzheimer’s disease have already been approved in the US and one of these, lecanemab, is under consideration by European and UK regulators. A third, donanemab, is expected this year and there are over 140 further treatments currently in clinical trials.

a. Ensuring the first disease-modifying treatments for dementia are available on the NHS
   • As DMTs for Alzheimer’s disease undergo regulatory review, it is imperative that the NHS proactively prepares for the opportunities and challenges these new treatments present.

\textsuperscript{16} Royal Society of Psychiatrists, National audit of dementia: Memory Assessment Services Spotlight Audit 2021, 2022.
\textsuperscript{17} Soren Mattke et al., in preparation
Following approval, collaborative efforts within the NHS are vital to expedite access to these treatments for patients.

- At £1.7bn, the current cost of dementia on the NHS is minimal compared to other disease areas. The symptomatic treatments we have available in the UK are cheap and patients don’t need routine monitoring. In contrast, new DMTs are expensive and will need careful monitoring - so as the first DMTs start arriving, an increase in NHS spend on dementia is inevitable.

- The NHS and industry need to agree a suitable price and explore “conditional access arrangements” to make sure that the first disease-modifying treatment for dementia is available on the NHS. The current government must play a leading role and the responsible minister should convene all parties now, rather than waiting for MHRA approval, to ensure that:
  - NHS England explores conditional access for promising new dementia treatments — this would enable longer-term data collection and provide the evidence needed by NICE to assess the full benefits of new dementia treatments.
  - NHS and industry meet in advance of MHRA approval to negotiate a price point that works for both parties, so that people can benefit from the treatment on the NHS as soon as the MHRA deem it safe.

b. Diagnostic capacity and clinical pathways to support new disease-modifying treatments for dementia

- Given that new treatments have a window of opportunity to be effective, at the early stages of disease progression, it is vital we have sufficient diagnostic capacity to find eligible patients who can benefit. Patients will need access to biomarker tests such as a PET scan, lumbar puncture, or, in the near future, a blood test. These diagnostic techniques are not routinely commissioned across England currently as part of the dementia clinical pathway. We need to support the development of more adaptable approaches to service delivery which integrate research, risk detection, diagnosis and treatment by creating a new clinical pathway for Alzheimer’s disease that supports people at all stages of disease progression. To achieve this, the Major Conditions Strategy must:
  - Work with the clinical community and the NHS to develop and implement a new clinical pathway for Alzheimer’s disease.
  - Support and invest in the roll-out of a network of Brain Health Clinics to deliver equitable, high-quality service across the UK. These should be commissioned by NHS Integrated Care Boards to ensure they meet local needs.

4. How can we make better use of research, data and digital technologies to improve outcomes for people with, or at risk of developing, the major conditions?

- Increased investment in dementia research over the last decade has led to significant advances. We are at a tipping point for progress, with the first generation of treatments that slow cognitive decline becoming available. This offers the potential to transform the lives of millions of people across the UK and enable the UK to benefit from the wave of investment that is likely to accompany recent treatment breakthroughs.

- Sustained investment at the right level, a strategic approach and a plan to embed and promote dementia research across the UK and harness the potential of data are vital to build on and accelerate further progress in developing new life-changing treatments.

‘Accelerating’ dementia research really resonates – as someone who has seen the devastation of dementia, and worries about getting dementia myself given family history, getting results as soon as possible seems vital’ (Policy Insight & Experience Panel Member).

a. Long-term strategic and sustainable plan for dementia research funding
• The Major Conditions Strategy is an opportunity for government to set out a long-term strategic and sustainable plan for dementia research funding, spanning experimental discovery science, translational science and clinical research. This should include:
  - Proactive government investment in clinical trials and data infrastructure.
  - Large-scale strategic initiatives like the UK Dementia Research Institute, which expand the UK’s science base while making the UK more attractive for investment.

b. Healthcare mission approach to dementia
• We believe an approach that brings stakeholders together to tackle dementia with key healthcare “missions” is the right one. The Dementia Mission and proposals for a dementia clinical trials network offer a promising basis. This approach must:
  - Provide a framework for increasing the UK’s share of dementia trials and accelerating the development and delivery of new treatments.
  - Focus on joining up key research initiatives to improve how we detect and diagnose the diseases that cause dementia, use healthcare data to speed up trials, and build innovation into trial delivery and regulation.

c. Embed and promote research across the UK
• Research must be representative of the population affected if we are to fully understand the diseases that cause dementia and develop appropriate treatments. To achieve this requires sustained government leadership and investment to:
  - Embed and promote research across all UK regions to increase and diversify participation, supporting areas which have less research activity and infrastructure.
  - Roll out brain health clinics across the UK to embed research into routine healthcare.

d. Harness the potential of data and digital technologies
• Currently, little healthcare data is collected and published about dementia leading to many gaps in our understanding. This hinders progress, yet technological advances offer tremendous potential for collecting data remotely to support early detection, to utilise digital cognitive tests for diagnosis and to monitor and support people living at home.

• Systems can identify suitable participants for research, monitor treatment (in healthcare and research settings), support service improvement and generate research insights. In order to fully realise this potential, better data linkage and access is needed across healthcare and research.

July 2023