

Executive Summary

By 2025, there will be over 1 million people living with dementia in the UK. Currently, there are no treatments that can delay the onset or slow the progression of the diseases that cause dementia. But with promising treatments in late stages of clinical trials, we need to prepare now so people living with dementia will be able to benefit from future treatments once they are developed.

To provide evidence of the potential impact and to highlight the need to prepare now for future treatments, Alzheimer's Research UK commissioned the London School of Economics and Political Science (LSE) Personal Social Services Research Unit (PSSRU) to model five hypothetical treatments for Alzheimer's disease, the most common cause of dementia. These were developed with advice from a clinical advisory group and reflect a likely treatment that may become available in the next five years as well as more speculative treatment scenarios, which were selected based on the direction of research.

This modelling is the first of its kind and designed to provide a platform from which to start a conversation about preparing for future treatments and it highlights a number of areas that we need to consider. This work must begin now, both to make sure the changes that are currently being made in access to medicines policy will work for dementia, and to ensure that there are no delays to patient access when treatments show success in clinical trials.

We urgently need to come together and think differently to prepare the healthcare system for such treatments.

To address these challenges, Alzheimer's Research UK is launching the Dementia Access Taskforce to bring together stakeholders from the NHS, NICE, government and industry to think differently about these challenges.

The healthcare system must begin to prepare for the scale and impact of future dementia treatments

Our analysis shows that a new treatment will have a large impact on the healthcare system, with between 310,000 and 750,000 people being eligible for treatment depending on the patient population in which each of our hypothetical treatments would be effective. This will require increased capacity in Memory Assessment Services, and a first-in-class treatment may also require reconfiguration of health services.

The cost of these treatments, and the long duration over which they would need to be taken, will also pose a challenge to the current system. For example, at a price point that would be considered cost-effective by NICE, the annual overall cost to the NHS of one of the treatment scenarios is estimated to be £420 million per year including £100 million for diagnosis.

Clearly, this poses serious questions about how a treatment will be funded and made available to those who would benefit. However the questions should not focus solely on overall cost; with an open-mind and willingness for innovation there are ways to address the challenges over longer time periods and to ensure savings made are recycled back into the system. We have a window of opportunity now to prepare for these treatments and ensure patient access.

1 Recommendation

There needs to be comprehensive horizon scanning in place to understand Alzheimer's treatments in development and their likely impact on the health sector.

2 Recommendation

The scale of the increased capacity and infrastructure changes required in the NHS needs to be scoped and considered now.

3 Recommendation

Innovative funding models should be developed to respond to the challenge of delivering future Alzheimer's treatments.

Early diagnosis will be vital for future treatments

Current scientific evidence suggests that disease-modifying treatments are likely to be most effective at the earlier stages of Alzheimer's. Our modelling shows that by treating earlier, people will live with mild symptoms for longer before these symptoms worsen, and there will be fewer people living with dementia. Moving towards earlier diagnosis will require an increase in public and health professional understanding that Alzheimer's starts long before symptoms are present. Therefore, it is necessary to scope the barriers and opportunities within the NHS to shifting towards earlier and biomarker-based diagnosis.

4 Recommendation

NHS England and NHS Improvement should support awareness and education around the molecular-based diagnosis of Alzheimer's and other dementias.

5 Recommendation

The government needs to work with charities to increase public awareness of the value of earlier detection for dementia.

6 Recommendation

The NHS needs to prepare to diagnose the diseases that cause dementia more accurately and at a much earlier stage, shifting to detection around 15 to 20 years earlier.

7 Recommendation

As recommended by the Edinburgh Consensus, the NHS should pilot specialist Brain Health Clinics to test an infrastructure that could incorporate developments in diagnostics and prepare the NHS for earlier diagnosis.

The value of dementia treatments to individuals and society may not be fully recognised in the current system

Alzheimer's has a huge impact on individuals, families and society. As well as its devastating personal impact, Alzheimer's disease alone accounts for £18 billion of the £26 billion total cost of dementia to the UK economy each year. An effective treatment would bring great value to people affected by this disease as well as wider society. The majority of this £18 billion is in social and informal care costs, yet savings that would be made in these sectors as a result of new treatments will not be completely captured in the current system of evaluating cost-effectiveness. It is vital that we understand the full value of a treatment and ensure that this is recognised as part of the assessment process.

8 Recommendation

The domains that reflect the true value of Alzheimer's treatments for individuals and society need to be identified, including where there are gaps in the data.