DEMENTIA IN THE UK

Estimating the potential future impact and return on research investment

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ohe.org
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Executive Summary

Government funding for dementia research peaked in 2018–19 (£112.9 million), but has since declined to about £105 million (Freeman, 2022), with this funding now covering a wider variety of neurodegenerative diseases. Investment in dementia research and medicine research and development (R&D) is significantly lower in comparison to other diseases such as cancer. However, recent breakthroughs and growing R&D pipeline show that this area has high potential for research over the next years. It is, therefore, important to estimate the benefits of dementia research to patients, their carers, the economy, and society.

The economic effects of dementia research on the economy can be understood through the lens of an economic impact assessment (EIA), which combines information from different dimensions of dementia research (e.g., investment- and employment– specific variables) and measures of economic impact (e.g., Benefit-Cost Ratio (BCR), the Full-Time Equivalent (FTE) and the Gross Value Added (GVA)). This is in line with methods indicated by the HM Greenbook guidelines (HM Treasury, 2022) and relevant reports by the Association of the British Pharmaceutical Industry (ABPI) and Cancer Research UK (CRUK) (ABPI and PwC, 2022; CRUK and PA Consulting, 2022).

This report contributes to the understanding of people’s proximity to dementia (e.g., people with dementia and their carers forecast) and so the potential future number of people who will be impacted by dementia, and the economic benefits arising from dementia research in the UK. These are summarised below.

i. Estimating people’s proximity to dementia and the effect on carers in the UK

We estimate that in 2040, over 1.2 million people in the UK will have dementia. This is an increase in prevalence of 30% from 2022. This increase in prevalence is driven by demographic ageing and assumes that the health care provided will remain the same.

When it comes to caring for people with dementia, we found that in 2022:

- 47% of people with mild young onset dementia (from those receiving a type of care) received community care.
- 18% of people with severe dementia (from those receiving a type of care), aged 65 and over, received nursing or residential care.
- 37% of informal carers supported people with severe dementia.
- 38% of informal carers spent more than 20 hours per week caring for a person with dementia.

We also found that COVID-19 had a significant impact on people with dementia:

- In 2020, dementia was the condition with the highest number of deaths from COVID-19 among people with a pre-existing condition.
- In 2021, 49% of the total care home deaths from COVID-19 among people with a pre-existing condition, was coming from people with dementia.
- In 2022, dementia was the main leading cause of death in both England and Wales.
We also seek to understand the lifetime risks associated with dementia, particularly in relation to the risk of developing dementia and the risk of becoming an informal carer. To do this, we model the lifetime risk of developing dementia, taking into account an average informal carer to patient ratio. We then estimate the risk of either developing dementia, becoming a carer, or both, by considering the lifetime risk of dementia if there is a genetic link to a person with dementia.

We find that currently:

- The likelihood of developing dementia in a lifetime is 36.2% (aprx. 1 in 2.75).
- The likelihood of becoming an informal carer for a person with dementia in a lifetime is 30.4% (aprx. 1 in 3).
- The likelihood of developing dementia, becoming an informal carer or both in a lifetime is 55% (aprx. 1 in 2).

**ii. Modelling the value of dementia research in the UK**

Figure 1 illustrates the dimensions, elements and indicators used to characterise the economic impact of dementia research in the UK.

**FIGURE 1: Investment in Dementia Research in the UK and its Economic Impact.**

When calculating the share of the UK in the current global interventional clinical trial pipeline, we found that:

- UK participants have been enrolled in 17% of 224 global (incl. UK) phase 3 clinical trials for dementia.
- UK participants have been enrolled in 17% of phase 3 clinical trials for Alzheimer’s disease.
- The vast majority of phase 3 clinical trials are industry-funded (96% and 84% for dementia and Alzheimer’s disease, respectively, and 100% for vascular, frontotemporal and Lewy Body dementia respectively).
- If UK people with dementia were included at the average participation rate of UK patients in all 224 global (incl. UK) phase 3 clinical trials for dementia, then 12,213 UK people living with dementia would have access to them.
- Access to 50 phase 3 global clinical trials would allow 2,895 UK people living with Alzheimer’s disease to participate.

When assessing the economic impact to society and economy generated by public and private investment in dementia research (which is wider and goes beyond the interventional clinical trials research), we found that:
• Dementia research totalled 7,353 full-time equivalent (FTE) jobs with over £529 million of gross value added (GVA) in 2019/20.
• Dementia research directly supported 2,607 FTE jobs of which 2,059 were research/scientific and technical jobs, and 548 were administrative jobs. This is associated with over £276 million of GVA.
• Dementia research supports and generates 4,746 indirect and induced FTE jobs, which are associated with over £252 million of GVA in 2019/20.
• **Every £1 invested in dementia research generated £2.59 of economic benefit in the UK during the period 2019/20.**
• **This is expected to increase to £2.91 on average in the next 20 years.** We estimate that every £1 invested in dementia research is expected to generate an average of £2.91 of economic benefits in the UK between 2020 and 2040.
• **Full-time salaries in dementia R&D are on average 41% higher than the average salary across all jobs in a region.** Accordingly, full-time salaries in dementia administration staff are on average 24.5% higher than the average salary across all jobs in a region.

In summary, we show that the impact of dementia on the UK population is significant and is predicted to increase and remain significant in the next 20 years. The study concludes that increased investment in dementia research and clinical trials not only has the potential to improve the lives of those with and affected by dementia, but also to create long-term economic growth and stability in the UK.
1. Introduction

The World Health Organisation defines dementia as a ‘term for several diseases that affect memory, thinking, and the ability to perform daily activities’ (World Health Organization, 2023). Dementia can create significant societal burden, with significant formal and informal carer requirements for many individuals living with dementia. Age is a risk factor for dementia (Alzheimer’s Society, 2023) and so as life expectancy continues to increase, the proportion of the population who are likely to develop dementia is increasing. Therefore, dementia is going to continue to burden individuals, their families and society.

Currently, dementia is the leading cause of death in both England and Wales (Office for National Statistics, 2023a). In 2020, dementia was the condition with the highest number of deaths from COVID-19 among people with a pre-existing condition in the UK (Office for National Statistics, 2023b). In 2021, it was the third pre-existing condition with 11,600 COVID-19 deaths, with 49.0% of the total care home deaths from COVID-19 among people with a pre-existing condition coming from people with dementia, and 9.4% of the total home deaths from COVID-19 among people with a pre-existing condition coming from people with dementia (Office for National Statistics, 2023b). In addition, COVID-19 has led to a backlog of people waiting for a dementia diagnosis, and therefore this has led to delays in accessing support (Department of Health and Social Care, 2022).

Government funding for dementia research peaked in 2018–19, but it has subsequently been declining to about £105 million year (Freeman, 2022), with this amount now taking into account a greater variety of neurodegenerative diseases.

Recent breakthroughs (i.e., lecanemab and aducanumab) and a growing R&D pipeline show that dementia is an area of high potential for research over the next years. It is therefore important to understand the benefits that dementia research can generate to people living with dementia, their carers, the economy, and society.

The aim of this report is to assess the current and future prevalence of dementia and its carers in the UK, as well as the economic benefits of investing in dementia research.

In section 2 of this report, we estimate the proximity to dementia in the UK, meaning we provide an analysis of the people living with dementia and their carer requirements. In particular, we provide an update of previous attempts to estimate the prevalence of dementia in the UK, providing projections for UK dementia prevalence until 2040. We also analyse the number of formal and informal carers for people living with dementia, projecting this to 2040 and calculating the lifetime risk (which is the probability of developing a disease during an individual’s life) of becoming an informal carer for someone with dementia. Furthermore, we update the previous estimation of the lifetime risk of developing dementia (Lewis, 2015), ensuring that the lifetime risk modelling methodology closely aligns with the methods used in the estimation of the cancer 1 in 2 statistic on the lifetime risk of developing cancer (Ahmad, Ormiston-Smith and Sasieni, 2015). Finally, we determine the lifetime risk of developing dementia, becoming an informal carer or both.

In section 3, we identify the current level of investment into dementia phase 3 interventional clinical trials in the UK and determine the potential impact of greater investment into dementia research. We determine the UK’s percentage of the global phase 3 interventional clinical trials pipeline and calculate the number of people in the UK who would have access to clinical trials if the country’s involvement in international dementia trials is expanded. Moreover, we evaluate the economic impact of public and private investment in dementia research, including the value added to society and the economy as a result of the research, and their estimates. In addition, we calculate the gross value added produced by jobs created around dementia research, thereby addressing economic disparities in the UK. Finally, we document regional effects demonstrating how dementia research-related R&D employment can increase local earnings.
2. Estimating the proximity to dementia in the UK

In this section, we provide the data and methods used to calculate the proximity to dementia in the UK. Firstly, we estimate the dementia prevalence in the UK in 2019 and provide projections until 2040. We also estimate the number of informal carers for people with dementia and project these figures to 2040. Informal carers are defined as individuals who assist senior family members, friends, and people in their social network who live inside or outside their household and require assistance with daily responsibilities, without receiving any financial reward (OECD, 2019; Peytrignet, Grimm and Tallack, 2023). Next, we calculate the lifetime risk of developing dementia and the lifetime risk of becoming a carer for someone living with dementia. Finally, we estimate the lifetime risk of developing dementia, becoming a carer or both. The approach is illustrated in the following figure:

**FIGURE 2: Estimating the proximity to dementia in the UK: The Approach.**

2.1 Methods and Data

2.1.1 Estimating the 2019 UK dementia prevalence

Evidence indicates that dementia incidence is declining over time (Ahmadi-Abhari et al., 2017). However, prevalence is likely to increase due to improved life expectancy. We conducted a targeted literature review to assess the current academic and policy-related evidence estimating the prevalence of dementia in the UK. We also used this literature review to identify evidence that would enable us to breakdown an overall prevalence estimate into different subgroups of the population (i.e., prevalence by age and gender) and to distribute the prevalence estimates to different dementia types, namely, Alzheimer’s Disease, Vascular Dementia, Dementia with Lewy bodies, Frontotemporal Dementia and Other Dementia and by disease stage, i.e., mild, moderate and severe.
Total UK prevalence

The Global Burden of Disease study is an observational epidemiological study that examines trends in 369 diseases and injuries in 204 countries and territories and is widely used internationally to understand health challenges and assess the impact of these on patient outcomes (The Lancet, 2023). We use the results of the 2019 Global Burden of Disease study to estimate the prevalence of dementia in the UK in 2019 (Nichols et al., 2022).

Young-onset dementia

We define young-onset dementia as the development of symptoms before the age of 65 (Dementia UK, 2023b). We assume that dementia prevalence is 0 for individuals below the age of 65 and so our young-onset prevalence will apply to 30- to 64-year-olds.

Wittenberg et al., (2019) estimates a population prevalence for 35-64-year-olds of 0.18% in the UK. We assume that this population prevalence rate also holds for 30–34-year-olds. Using the ONS population estimates for 2019 (males: 14,903,095 females: 15,258,775) and assuming males and females are equally likely to develop young onset dementia, as indicated in Prince et al., (2014) we estimate the young-onset dementia prevalence in 2019.

Dementia in individuals aged 65 and over

The gender-specific population rates of individuals aged 85 plus are taken from the CFAS (Cognitive Function and Aging) II study (Matthews et al., 2016), shown in Table 1. Applying these to the ONS 2019 population rates provides us with the 2019 dementia prevalence in those aged 85 and over.

We calculate the prevalence for individuals between 65 and 85 by subtracting the 85 plus and young-onset 2019 dementia prevalence from the total prevalence. We then impose the assumption that dementia prevalence doubles every five years until the age of 85 (as identified by the National Institute of Aging (2019) NHS England (2023) and O’Brien and Thomas (2015)).

Dementia by disease stage

We use the definitions of mild, moderate and severe stages of dementia and the estimations of their proportion of the population from Wittenberg et al. (2019). These are used to estimate the proportion of dementia cases at each disease stage by age group, shown in Table 1.

<table>
<thead>
<tr>
<th>TABLE 1: Proportion of individuals living with dementia (in each disease type).</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proportion of individuals with dementia (Wittenberg, 2019)</td>
</tr>
<tr>
<td>30-64 yrs</td>
</tr>
<tr>
<td>Mild</td>
</tr>
<tr>
<td>Moderate</td>
</tr>
<tr>
<td>Severe</td>
</tr>
</tbody>
</table>

Dementia by disease type

There are over 200 types of dementia (Dementia UK, 2023a), but in this analysis we focus on some of the most common types, namely, Alzheimer’s disease, Vascular Dementia, Dementia with Lewy bodies, Frontotemporal Dementia and group all other dementia types into a group we call ‘Other Dementia’.
To determine the proportion of dementia prevalence attributable to each type of dementia we use estimates from Prince et al. (2014). However, these estimates are only applicable to dementia in those aged 65 and over.

According to the Alzheimer’s society, 1 in 3 people with young-onset dementia have Alzheimer’s disease (Alzheimer’s Society, 2023). We assume that the proportion of other dementia’s is equal to the proportion in the 65 plus age group. Dementia with Lewy Bodies is estimated to account for between 1 and 7% of young-onset dementia cases (Vieira et al., 2013) – we use the midpoint (4%) for our analysis. Vascular and Frontotemporal dementia prevalence are assumed to be greater than in the 65 plus age group and are likely to be the second most common types of dementia (Vieira et al., 2013) and so the proportion of dementia cases in these types is equal to the remainder of the proportion not attributed to Alzheimer’s disease, Dementia with Lewy Body and other types.

The proportion of people with dementia with each type of dementia by age group is shown in Table 2.

### TABLE 2: Proportion of individuals living with dementia (by disease type).

<table>
<thead>
<tr>
<th>Proportion of individuals with dementia</th>
<th>Young-Onset (30-64 yrs)</th>
<th>65 yrs + (Prince et al, 2014)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Alzheimer’s Disease</td>
<td>33%</td>
<td>62% (Alzheimer’s Society, 2023)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>24% (Vieira et al, 2013)</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td></td>
<td>17%</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>4%</td>
<td>4% (Vieira et al, 2013)</td>
</tr>
<tr>
<td>Frontotemporal Dementia</td>
<td>24%</td>
<td>2% (Vieira et al, 2013)</td>
</tr>
<tr>
<td>Other Dementia</td>
<td>15%</td>
<td>15%</td>
</tr>
</tbody>
</table>

2.1.2 Projecting UK dementia prevalence to 2040

To project the 2019 dementia prevalence to 2040 we apply the population prevalence rates to the latest projected annual populations for the UK - the 2020-based ONS population projections (Office for National Statistics, 2022b). In these estimations we do not incorporate the potential impact of any modifiable risk factors and change in health care provided (such as new treatments), and as we assume that the age-specific prevalence remains at a constant proportion of the population, any increases in prevalence are driven only by demographic aging. We also rely on the assumption that the ONS population predictions are realistic.

We also assume that the gender-specific proportion of dementia cases that are young-onset and occurring in each age group over 65 remain constant across the projection period. It is also assumed that the proportion of dementia cases in each stage and each type remains constant over the projection period.

2.1.3 The lifetime risk of developing dementia

Lifetime risk is the probability of developing a disease in the course of an individual’s remaining life span (Nguyen and Nguyen, 2008; NIH, 2023). The approach taken in our analysis to estimate the lifetimes risk of developing dementia aligns with the lifetime risk modelling approach used to generate the well-known 1 in 2 cancer statistic (Ahmad, Ormiston-Smith and Sasieni, 2015). We
estimate the model assuming a maximum length of life of 100 years (i.e., the model is estimated over ages 0-99).

As set out in appendix 1 of Ahmadi et al. paper (2015):

The probability of being at risk of dementia (i.e., alive and without a previous diagnosis of dementia) at age \(i\) is \(\hat{S}_d(i) = \exp(-\sum_{j=0}^{\text{99}}(\lambda_j))\), where \(\lambda_i = r_i + m_i + d_i\) is the hazard of no longer being alive and dementia free and \(r_i\) is the dementia incidence at age \(i\); \(m_i\) is the all causes mortality rate at age \(i\); \(d_i\) is the dementia mortality rate at age \(i\).

The lifetime risk at age \(i\) (\(l_i\)) is:

\[
l_i = \hat{S}_d(i) \times r_i x \frac{1 - \exp(-\lambda_i)}{\lambda_i}, \text{ for } i = 0, 1, \ldots, 98
\]

And \(l_{99} = \hat{S}_d(99) \times r_{99} x \frac{1}{\lambda_{99}}\). The lifetime risk for a cohort born in \(y\) is \(LR_y(y) = \sum_{i=0}^{99} l_i(y + i)\).

To estimate the incidence of dementia in individuals aged 60 and over we use the findings from the CFAS II study (Matthews et al., 2016). We assume that dementia incidence in individuals aged 0 to 30 is zero, aligning with our assumption that prevalence is 0 in these age groups. To estimate incidence in the 30-64 age group (young-onset dementia), we use prevalence and life expectancy data. We rely on the prevalence assumption that 0.18% of the population have young onset dementia (Wittenberg et al., 2019) and that the life expectancy for dementia specific from the time of diagnosis are: Alzheimer’s Disease: 9.6 years; Vascular: 6 years (Vieira et al., 2013); Lewy Body: 6 years and Frontotemporal: 7 years (Alzheimer’s Society, 2021). For other dementias we use the average young onset life expectancy of 8.6 years (Vieira et al., 2013).

We use the estimated proportion of the population in age-group with each type of dementia (prevalence) divided by the average life expectancies to estimate an incidence rate for each age between 30 and 99. Incidence is assumed to remain constant. However, as previously mentioned, evidence suggests that this incidence is declining over time (Ahmadi-Abhari et al., 2017; Matthews et al., 2016) and so this statistic is likely to be an overestimation. Our assumption that incidence remains constant is not expected to cause any significant change to the estimated lifetime risk.

To estimate the dementia mortality rate we use 2019 ONS data for England and Wales (Office for National Statistics, 2023b), with the mortality rates of England and Wales being extrapolated to cover the whole of the UK. The period mortality rates (i.e., 2019 age-specific mortality rates) are also derived from ONS data (Office for National Statistics, 2023a). The lifetime risk model relies on the assumption that the mortality rates for each age group in 2019 apply to all birth cohorts when they reach that respective age group. For example, for babies born in 2019 we assume that the mortality rate when they are 50 in 2069 will be the same as the mortality rate for those who are 50 in 2019 (who were born in 1969). This use of period mortality rates was used by Lewis (2015) in their estimation of the lifetime risk of developing dementia.

2.1.4 Carer analysis

Formal Care

Formal care is funded care provided by a trained professional. The care can be paid for by the individual receiving care (or their friends or family) or can be state funded. We estimate the number and proportion of people with dementia who receive formal care in the community and

---

1 The average life expectancies used for Dementia with Lewy bodies and Frontotemporal dementia are calculated for dementia in those aged 65 and over (Alzheimer’s Society, 2021).
nursing/residential care by disease stage and type of care. To do this we use data on Adult Social Care Statistics collected from NHS digital (2022). Type of care is broken down into two categories: nursing or residential care, and community care. Nursing or residential care refers to care provided outside of a person’s home, i.e., where a person with dementia has moved from their home to receive care. Community care refers to any formal care provided in a person’s home.

Informal Care
Informal care is unpaid care, often provided by family, friends or other loved ones. We combine information on prevalence by age-group and disease stage and calculate the actual number and proportion of people who receive care.

Evidence suggests that for every 100 people with dementia, 84 other people provide informal care (NICE, 2006; Lakey et al., 2012; Lewis et al., 2014). We use this carer-to-patient ratio of 0.84, combined with our dementia prevalence estimates by age-group and disease stage, to calculate the actual number and proportion of people who receive care; therefore, assuming each carer only provides informal care for one person the living with dementia, this would also be the number of carers required. We calculate the number of carers by gender and by disease stage of the person living with dementia for 2019 and then forecasted to 2040 using the ONS population projection estimates (Office for National Statistics, 2022b). For calculating the number of female and male carers we assumed that 60% of the total carers (for all diseases) are female (Aldridge and Hughes, 2016).

We also estimate the amount of time carers spend caring for the individual living with dementia per week. For these estimations, we use the statistics on carer time burden presented in Aldridge and Hughes (2016).

2.15 Lifetime risk of developing dementia; being an informal carer or both
We use our estimation of the lifetime risk of developing dementia and lifetime risk of being an informal carer (see results) to estimate a combined figure that provides the lifetime risk of developing dementia, becoming a carer or both.

To estimate the likelihood of being a carer and developing dementia we use the estimation that 26% of people with dementia are cared for by their child (Lewis et al., 2014; Wimo et al, 2013). We assume that this figure refers purely to genetic children; so we use the assumption that the lifetime risk of dementia if there is a genetic link to a person with dementia is double compared to those without (Loy, 2014) to estimate the lifetime risk of becoming a carer and having dementia if you have a genetic link to the person you are caring for. We are then able to estimate the lifetime risk of developing dementia and becoming a carer for those who do not have a genetic link. Applying these lifetime risks to an illustrative population of 100 we can then separate out the estimated number of individuals who will develop dementia in their lifetime and add the carers who do not develop dementia, both with or without a genetic link. This provides us with the number of people with dementia (whether they are carers or not) or are a carer or both.

2.2 Results

2.2.1 Dementia prevalence estimates

The global burden of disease study estimates that in 2019 there were 907,331 people in the UK living with dementia. We estimate that of these, 54,291 were aged between 30 and 64 years (young-onset dementia) and the remaining 853,040 were aged 65 years and over.
We estimate that in the UK there will be over a million people in the UK living with dementia in 2026, with over 1.22 million (1,220,193) people in 2040. With our assumptions, in 2040 there will be 54,880 people with young-onset dementia and 1,165,313 people aged 65 and over with dementia. Due to minimal changes in the expected population between the ages of 30 and 64 there is relatively little change between the 2019 and 2040 estimates. However, due to the increase in life expectancy, there is a significant increase in the number of people living with dementia aged 65 and over.

Table 3 shows how the breakdown of the 2019, 2023 and 2040 prevalence estimates by gender, disease stage and disease type. Full tables are provided in the Appendix.

**TABLE 3: Estimated number of people with dementia in the UK in 2019, 2023 and 2040.**

<table>
<thead>
<tr>
<th>Sub-Group</th>
<th>Young Onset (30-64)</th>
<th>65 +</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>2019</td>
<td>2023</td>
</tr>
<tr>
<td>Total</td>
<td>54,291</td>
<td>55,263</td>
</tr>
<tr>
<td>Male</td>
<td>27,146</td>
<td>27,565</td>
</tr>
<tr>
<td>Female</td>
<td>27,146</td>
<td>27,565</td>
</tr>
<tr>
<td>Mild</td>
<td>30,162</td>
<td>30,702</td>
</tr>
<tr>
<td>Moderate</td>
<td>18,097</td>
<td>18,421</td>
</tr>
<tr>
<td>Severe</td>
<td>6,032</td>
<td>6,140</td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>17,916</td>
<td>18,237</td>
</tr>
<tr>
<td>Vascular Dementia</td>
<td>13,030</td>
<td>13,263</td>
</tr>
<tr>
<td>Dementia with Lewy bodies</td>
<td>2,172</td>
<td>2,211</td>
</tr>
<tr>
<td>Frontotemporal Dementia</td>
<td>13,030</td>
<td>13,263</td>
</tr>
<tr>
<td>Other Dementia</td>
<td>8,144</td>
<td>8,289</td>
</tr>
</tbody>
</table>

Note: Values are rounded. Source: Authors’ calculations.

**2.2.2 Carer estimates**

Dementia carers are estimated to be 791,210 in 2022, while it is expected that this number will increase up to 1,025,000 in 2040 (Figure 3).

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*For the forecast, we assume that the level of care remains the same as today, e.g., no new treatment is introduced.*
Moreover, the results show that the number of dementia carers for the severe stage of the disease will increase by 31% from 2022 to 2040. Figure 4 illustrates the number of dementia carers by disease stage to 2040.

Specifically, in 2022, 37% of carers support people with severe dementia and 47% of carers support people with mild or moderate dementia (Table 4).
TABLE 4: Share of carers by disease stage.

<table>
<thead>
<tr>
<th>Stage</th>
<th>Share of carers by disease stage (all dementias)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mild</td>
<td>16%</td>
</tr>
<tr>
<td>Moderate</td>
<td>31%</td>
</tr>
<tr>
<td>Severe</td>
<td>37%</td>
</tr>
</tbody>
</table>

Note: There is also a 16% of carers referring to other stages and includes dementia that has not been characterised as mild, moderate, or severe and dementia stages that are in between of those documented.

In terms of carers’ time burden, we find that 38% of carers spend more than 20 hours per week caring for a person living with dementia, while 45% of carers spend up to 10 hours per week caring for a person living with dementia.

FIGURE 5: Number of dementia carers forecast (by working hours per week).

Finally, in Figure 6, we illustrate the number of people who need community or residential care across different age-groups over the next years. Accordingly, Figure 7 shows the proportion of people receiving a type of care. For instance, we find that 47% of people (from those who receive a type of care) with mild young onset dementia receive community care, while 18% of people (from those who receive a type of care) with severe dementia, aged 65 and over, receive nursing or residential care.
2.2.3 Lifetime risk analysis

The lifetime risk of developing dementia in the UK is 36.2%. This is approximately 1 in 2.75. Therefore, this is consistent with the 1 in 3 statistic developed by Lewis (2015).

The lifetime risk of becoming an informal carer is 30.4%. This can also be interpreted as 1 in 3. It is calculated by multiplying the lifetime risk of developing dementia with the average informal carer to patient ratio of 0.84 from Lewis (2015).
Finally, we estimate that the lifetime risk that an individual will become a carer for a parent with dementia (i.e., people with a genetic link) is 57.5%, decreasing to 28.7% for those without a genetic link. Therefore, we estimate that **55% or approximately 1 in 2 people risk developing dementia or becoming a carer or both in their lifetime**. Figure 8 provides an illustration of the lifetime risk model results using a population of 100.

**FIGURE 8: Lifetime risk illustration.**

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In this section, we calculate the share of the UK in the global phase 3 interventional clinical trial pipeline. Then, we measure the number of UK patients who could have access to current phase 3 interventional clinical trials if UK participation in global dementia trials is increased. This is then followed by an assessment of the economic impact generated from public and private investments in dementia research and their projections, measured as the value added to the society and economy (which is wider and goes beyond the interventional clinical trials research). Finally, we estimate the gross value added generated by creating jobs around dementia research, therefore tackling economic inequalities across the UK. We also capture regional effects showing that jobs in dementia R&D promote growth in local wages. Our approach is summarised in Figure 9.

**FIGURE 9: Modelling the value of dementia research in the UK: The Approach.**
To document the number of clinical trials for dementia, we utilised the U.S. National Library of Medicine clinicaltrials.gov database (ClinicalTrials.gov, 2023), as this is the most comprehensive clinical trials registry (Venugopal and Saberwal, 2021) and was used in previous dementia pipeline analysis (Marsden and Mestre-Ferrandiz, 2015).

We collected data on phase 3 clinical trials for different types of dementia (including Alzheimer’s disease, vascular, frontotemporal, dementia with Lewy bodies, young onset and mixed dementias). The phase 3 clinical trials in our sample had one of the following statuses as of the 30th January 2023: “Active, Not recruiting”, “Completed”, “Enrolling by invitation”, “Recruiting”.

For each trial we gathered information on the funder to ascertain whether funding came from private (i.e., industry-funded trials such as pharmaceutical or medical device companies) or public (i.e., government funded) organisations. We use the ‘funder type’ field in the US National Library of Medicine database, which describes the organisation that provides support for a clinical trial. This support may include activities related to funding, design, implementation, data analysis, or reporting. Organisations listed as sponsors and collaborators for a study are also considered the funders of the study. Finally, only interventional clinical trials were considered.

The analyses around the UK’s share of the current dementia clinical trial pipeline, as well as the number of UK patients who could benefit from access to clinical trials if UK participation in global dementia trials was increased, is based on our own calculations, as detailed below.

In multi-site trials, we assume equal distribution of the patients enrolled in the phase 3 trial across the countries that participated in the trial. The number of UK patient enrolment in phase 3 clinical trials is calculated as follows:

$$\text{UK patient enrolment} = \left( \frac{\text{total enrolment}}{\text{number of sites}} \right) \times \text{number of UK sites}$$

The number of patients who could benefit from access to global phase 3 clinical trial is calculated as follows:

$$\text{UK patients who could benefit} = \frac{\text{average number of UK patients in phase 3 clinical trials}}{\text{additional number of global phase 3 clinical trials}}$$
### 3.12 Results

#### 3.12.1 Share of the UK in the global clinical trials pipeline

The analysis of the share of the UK in the global clinical trials pipeline reveals that **UK participants have been enrolled in 17.4% of phase 3 clinical trials for dementia**. The UK participants make up 2.5% of the total phase 3 clinical trials participants for dementia worldwide. The vast majority (96%) of phase 3 clinical trials taking place in the UK for dementia are industry-funded. Also, the average number of UK phase 3 clinical trial sites is seven per trial, and the average number of global phase 3 clinical trial sites for dementia is approximately 134 per trial. The boxes below provide more details of the results for each of the examined dementia type. For a graphical presentation of the results, please see the Appendix.

![FIGURE 10: Share of the UK in the global clinical trials pipeline.](image)

#### Alzheimer’s Disease
- There are 191 phase 3 clinical trials worldwide and 32 in the UK.
- These trials have enrolled 113,837 patients worldwide.
- UK participants have been enrolled in 16.75% of the phase 3 clinical trials.
- The number of patient enrolments in phase 3 clinical trials in the UK is 1,853 (share: 1.63%)
- 84.38% of phase 3 clinical trials in the UK are funded by the industry.
- 68.06% of phase 3 CTs worldwide are funded by the industry.

#### Vascular Dementia
- UK participants have been enrolled in 11.11% of phase 3 clinical trials.
- 7,909 patients have been enrolled in phase 3 clinical trials worldwide.
- The number of patient enrolments in phase 3 clinical trials in the UK is 18.9 (share: 1.23%)
- There are 18 phase 3 clinical trials worldwide and 2 in the UK.
- 100% of phase 3 clinical trials in the UK are funded by the industry.
- 72.22% of phase 3 CTs worldwide are funded by the industry.

#### Frontotemporal Dementia
- UK participants have been enrolled in 44.44% of phase 3 clinical trials.
- 1,197 patients have been enrolled in phase 3 clinical trials worldwide.
- The number of patient enrolments in phase 3 clinical trials in the UK is 72.54 (share: 6.06%).
- There are 9 phase 3 clinical trials worldwide and 4 in the UK.
- 100% of phase 3 clinical trials in the UK are funded by the industry.
- 66.67% of phase 3 CTs worldwide are funded by the industry.

#### Lewy Body Dementia
- UK participants have been enrolled in 16.67% of phase 3 clinical trials.
- 1,775 patients have been enrolled in phase 3 clinical trials worldwide.
- The number of patient enrolments in phase 3 clinical trials in the UK is 18.89 (share: 1.06%).
- There are 6 phase 3 clinical trials worldwide and 1 in the UK.
- The only phase 3 clinical trial in the UK is funded by the industry.
- 66.67% of phase 3 CTs worldwide are funded by the industry.

---

3 Including participation in multi-site trials. In this analysis, dementia phase 3 clinical trials include trials for Alzheimer’s disease, Vascular dementia, Frontotemporal dementia, and Lewy Body dementia. At the time of this study, there were no phase 3 clinical trials for mixed dementia in the UK.
Further examination of the clinical trials data shows that if UK participants were included at the average participation rate in all 224 global phase 3 clinical trials for dementia, then 12,213 UK people (six times higher than they currently are) living with dementia would have access to them and therefore, the potential to benefit. Figure 11 presents the breakdown of the results by dementia type.

**FIGURE 11: Accessing global clinical trials by dementia type.**

### Alzheimer’s Disease
- If UK participants were included at the average participation rate in all 191 global phase 3 clinical trials, then 11,059 UK people living with Alzheimer’s disease would have access to these trials.
- Access to 50 phase 3 global clinical trials would allow 2,895 UK people living with Alzheimer’s disease to participate.
- The average participation in the global phase 3 Alzheimer’s disease clinical trials is 629 patients per trial.
- The average number of UK participants per phase 3 Alzheimer’s disease clinical trial is 58.

### Vascular Dementia
- If UK participants were included at the average participation rate in all 18 global phase 3 clinical trials, then 878 UK people living with Vascular dementia would have access to these trials.
- Access to ten phase 3 global clinical trials would allow 488 UK people living with Vascular dementia to participate.
- The average participation in the global phase 3 Vascular dementia clinical trials is 465 patients per trial.
- The average number of UK participants per phase 3 Vascular dementia clinical trial is 49.

### Frontotemporal Dementia
- If UK participants were included at the average participation rate in all 9 global phase 3 clinical trials, then 163 UK people living with Frontotemporal dementia would have access to these trials.
- Access to five phase 3 global clinical trials would allow 91 UK people living with Frontotemporal dementia to participate.
- The average participation in the global phase 3 Frontotemporal dementia clinical trials is 133 patients per trial.
- The average number of UK participants per phase 3 Frontotemporal dementia clinical trial is 18.

### Lewy Body Dementia
- If UK participants were included at the average participation rate in all 6 global phase 3 clinical trials, then 113 UK people living with Lewy Body dementia would have access to these trials.
- Access to five phase 3 global clinical trials would allow 94 UK people living with Lewy Body dementia to participate.
- The average participation in the global phase 3 Lewy Body dementia clinical trials is 296 patients per trial.
- The average number of UK participants per phase 3 Lewy Body dementia clinical trial is 19.
3.2 Economic impact assessment of dementia research in the UK

In this part of the analysis, we quantify the economic impact and the associated benefits of dementia research in the UK. We aim to assess the economic impact to society and the economy generated by public and private investment in dementia research and to provide projections of how this impact is likely to change in the future. We also estimate the gross value added generated by creating jobs around dementia research, therefore tackling economic inequalities across the UK.

3.2.1 Methods and data

We suggest that the economic effects of dementia research on the economy can be understood through the lens of an economic impact assessment (EIA), which combines information from different dimensions of dementia research (e.g., investment- and employment-specific variables) and measures of economic impact (e.g., Benefit-Cost Ratio (BCR), the Full-Time Equivalent (FTE) and the Gross Value Added (GVA)). Positive effects of dementia research to the UK economy are mainly captured when the BCR>1, meaning that every £1 invested in dementia research generates more than £1 of economic benefit in the UK.

The methodology applied for the economic impact assessment of dementia research in the UK is supported by advice provided in the HM Treasury Green Book and builds on prior work in the field of economics (e.g., (CRUK and PA Consulting, 2022)). To ensure transparency and replicability of our results, we utilise publicly available databases.

The main indicators which are investigated and incorporated to conduct this economic impact assessment are the following:

- **The term "full time equivalent" (FTE) refers to the number of full-time jobs that a certain investment may sustain. Since FTEs are used rather than a simple headcount, comparisons can be conducted even though the percentage of part-time employment differs between industries or/and organisations.**

- **A measure of net economic output, gross value added (GVA) refers to the contribution of a sector or region to the national gross domestic product (GDP). It is determined by subtracting the value of inputs from the value of production.**

- **Direct benefits** indicate the operational expenditure of dementia research organisations on employee salaries and consider all roles. When dementia research organisations spend money on products and services that serve as inputs for their operations, this is referred to as receiving **indirect benefits**. This expenditure provides money to suppliers, who then purchase goods and services from other businesses, influencing the entire supply chain.

- **Induced benefits** are generated from the direct and indirect impacts. Those who are employed directly by dementia research organisations or indirectly by firms in the dementia research supply chain receive a wage that is used to acquire products and services by employees in their local economy which gives rise to an additional ripple effect beyond the dementia research supply chain.

- **Benefit-cost ratio (BCR)** is a metric that illustrates how a project’s relative costs and benefits—expressed in monetary or qualitative terms—relate to one another. A project is anticipated to provide a firm and its investors with a positive net present value if its BCR is greater than 1.0.
We also conduct further analysis, investigating the regional effects of dementia research on salaries. Specifically, we compared the salaries in R&D and administrative positions with the average regional salaries in areas where the Alzheimer’s Research UK Research Network is based. For the average earnings by region we used the House of Commons report and then we compared them as a share of the salaries for R&D and administrative staff (Francis-Devine, 2023).

Finally, all the data sources and formulas used for this section are presented in the Appendix (Tables A5 and A6).

### 3.2.2 Results

#### 3.2.2.1 Aggregate full-time equivalent (FTE) and gross value added (GVA)

Our analysis suggests that dementia research totalled 7,353 full-time equivalent (FTE) jobs with £529,089,886 of gross value added (GVA) in 2019/20. Specifically, dementia research directly supported 2,607 FTE jobs from which 2,059 were research/scientific and technical jobs, while 548 refer to administrative jobs. This is associated with £276,287,147 of GVA. Moreover, dementia research supports and generates 4,746 indirect and induced FTE jobs, which are associated with £252,802,739 of GVA.

---

**Multipliers (e.g., FTE, GVA):** If there is an increase in final use for a particular industry output, we can assume that there will be an increase in the output of that industry, as producers react to meet the increased use; this is the direct effect. As these producers increase their output, there will also be an increase in use on their suppliers and so on down the supply chain; this is the indirect effect. As a result of the direct and indirect effects the level of household income throughout the economy will increase as a result of greater employment. A proportion of this increased income will be re-spent on final products, this is the induced effect. The ability to quantify these multiplier effects is important as it allows economic impact analyses to be carried out on the economy. Type I multipliers sum together direct and indirect effects while Type II multipliers also include induced effects. (Scottish Government - Chief Economist Directorate, 2022)

**GVA Multiplier:** The ratio of the direct GVA change to the indirect GVA change (and induced GVA change if Type II multipliers are applied). In other words, if you have the change in GVA for the industry, the GVA multiplier can be used to calculate the change in GVA for the economy (Scottish Government - Chief Economist Directorate, 2022).

**Full-time equivalent (FTE) / employment multiplier:** The ratio of direct plus indirect (plus induced if Type II multipliers are used) employment changes to the direct employment change. In other words, if you have a change in FTE employment for the industry the employment multiplier can be used to calculate the change in FTE employment for the economy (Scottish Government - Chief Economist Directorate, 2022).
3.2.2.2 Indirect benefits across sectors

Dementia research stimulated 2,415 indirect FTE jobs related to scientific research and development services and 274 indirect FTE jobs in wholesale trade services. The scientific indirect jobs provided an additional output of £121,232,523, while £13,747,711 were generated in wholesale trade services (Table 5). Figure 14 shows the sectoral breakdown of indirect benefits of dementia research.

TABLE 5: Total indirect FTE and GVA benefits.
Our findings in Table 6 show that the BCR of dementia research is 2.59, which means that every £1 invested in dementia research generated £2.59 of economic benefit in the UK during the period 2019/20.
In order to forecast the BCR to 2040, we assume 3% of an annual increase in investment and also incorporate inflation forecasts. We find that the average benefit-cost-ratio (BCR) from 2020 to 2040 will be 2.91, meaning that every £1 invested in dementia research is expected to generate an average of £2.91 of economic benefits in the UK between 2020 and 2040. This is presented in Table 6. Table 7 provides a detailed forecast on the investment, FTE, GVA and BCR in dementia research for the upcoming years.

**TABLE 6: BCR of dementia research to 2040.**

<table>
<thead>
<tr>
<th>Year</th>
<th>BCR</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019/20</td>
<td>2.59</td>
</tr>
<tr>
<td>2025</td>
<td>2.88</td>
</tr>
<tr>
<td>2030</td>
<td>2.90</td>
</tr>
<tr>
<td>2035</td>
<td>3.03</td>
</tr>
<tr>
<td>2040</td>
<td>3.15</td>
</tr>
<tr>
<td>Average</td>
<td>2.91</td>
</tr>
</tbody>
</table>

Finally, in Table 8, we provide the estimates for 2024 which are based on the national mission for dementia investment (Prime Minister's Office et al., 2022). If the national mission of dementia investment is achieved, the BCR for 2024 would be 3.96, and the average BCR between 2020 and 2040 would be approximately 3.09.

**TABLE 7: Economic impact forecast to 2040.**

<table>
<thead>
<tr>
<th>Year</th>
<th>Investment</th>
<th>FTE</th>
<th>GVA</th>
<th>BCR</th>
</tr>
</thead>
<tbody>
<tr>
<td>2019/20</td>
<td>£204,165,000</td>
<td>7,353</td>
<td>£529,089,886</td>
<td>2.59</td>
</tr>
<tr>
<td>2025</td>
<td>£227,157,480</td>
<td>9,102</td>
<td>£654,969,320</td>
<td>2.88</td>
</tr>
<tr>
<td>2030</td>
<td>£228,426,683</td>
<td>9,204</td>
<td>£662,308,823</td>
<td>2.90</td>
</tr>
<tr>
<td>2035</td>
<td>£238,530,979</td>
<td>10,036</td>
<td>£722,198,289</td>
<td>3.03</td>
</tr>
<tr>
<td>2040</td>
<td>£247,999,018</td>
<td>10,849</td>
<td>£780,668,752</td>
<td>3.15</td>
</tr>
<tr>
<td>Average</td>
<td>£229,255,832</td>
<td>9,309</td>
<td>£669,847,014</td>
<td>2.91</td>
</tr>
</tbody>
</table>

**TABLE 8: Economic impact forecast in 2024 with the national mission for dementia investment achieved.**

<table>
<thead>
<tr>
<th>Year</th>
<th>Investment</th>
<th>FTE</th>
<th>GVA</th>
<th>BCR</th>
</tr>
</thead>
<tbody>
<tr>
<td>2024</td>
<td>£247,999,018</td>
<td>10,849</td>
<td>£780,668,752</td>
<td>3.96</td>
</tr>
<tr>
<td>Average</td>
<td>£229,255,832</td>
<td>9,309</td>
<td>£669,847,014</td>
<td>3.09</td>
</tr>
</tbody>
</table>
Overall, the current BCR of dementia research is high and very close to the BCR indicated by CRUK (2.8) for cancer research (CRUK and PA Consulting, 2022). This means that the impact of dementia research would be even greater if there were novel treatments for dementia available which would lead to improved health outcomes and therefore more benefits to the economy.

### 3.3 Regional effects

Capturing the regional effects of dementia research shows how jobs within the spectrum of dementia research can promote growth in local wages.

Dementia research has a presence in all four countries of the UK and all regions of England. We find that full-time salaries in dementia R&D are on average 41% higher than the average salary across all jobs in a region. Accordingly, full-time salaries in dementia admin staff are on average 24.5% higher than the average salary across all jobs in a region. The results presented in Table 9 and Figure 15 show the significant positive effects that dementia research has on salaries at the regional level by creating well-paid jobs, and therefore increasing the living standards locally and tackling inequalities across the UK. For instance, we find that the salary effect of dementia research in regions such as North England, which has the highest unemployment rate in the UK (5.7%) (Office for National Statistics, 2022a), Yorkshire and Northern Ireland, which have the highest economic inactivity rates (24.4% and 27.6%, respectively) (Office for National Statistics, 2022a) is stronger compared to other regions (e.g., London).

**TABLE 9: Regional salary comparisons (dementia research vs average local salary).**

<table>
<thead>
<tr>
<th>Region</th>
<th>R&amp;D staff salary vs average local salary</th>
<th>Admin staff salary vs average local salary</th>
</tr>
</thead>
<tbody>
<tr>
<td>East</td>
<td>+34.3%</td>
<td>+18.6%</td>
</tr>
<tr>
<td>Wales</td>
<td>+48.5%</td>
<td>+31.1%</td>
</tr>
<tr>
<td>London</td>
<td>+17.3%</td>
<td>+3.5%</td>
</tr>
<tr>
<td>North West</td>
<td>+48.5%</td>
<td>+31.1%</td>
</tr>
<tr>
<td>Midlands</td>
<td>+47.4%</td>
<td>+30.2%</td>
</tr>
<tr>
<td>North</td>
<td>+51.6%</td>
<td>+33.8%</td>
</tr>
<tr>
<td>Northern Ireland</td>
<td>+51.8%</td>
<td>+34%</td>
</tr>
<tr>
<td>Thames Valley</td>
<td>+25.2%</td>
<td>+10.6%</td>
</tr>
<tr>
<td>Scotland</td>
<td>+40.2%</td>
<td>+23.8%</td>
</tr>
<tr>
<td>South Coast</td>
<td>+31%</td>
<td>+15.6%</td>
</tr>
<tr>
<td>South West</td>
<td>+44.7%</td>
<td>+27.8%</td>
</tr>
<tr>
<td>Yorkshire</td>
<td>+51%</td>
<td>+33.3%</td>
</tr>
<tr>
<td><strong>All</strong></td>
<td><strong>+41%</strong></td>
<td><strong>+24.5%</strong></td>
</tr>
</tbody>
</table>
FIGURE 15: Regional salary comparisons in areas where the Alzheimer’s Research UK Research Network is based.

Scotland
+40.2% (R&D)
+23.8% (Admin)

Northern Ireland
+51.8% (R&D)
+34% (Admin)

North
+51.6% (R&D)
+33.8% (Admin)

Yorkshire
+51% (R&D)
+33.3% (Admin)

Midlands
+47.4% (R&D)
+30.2% (Admin)

East
+34.3% (R&D)
+18.6% (Admin)

London
+17.3% (R&D)
+3.5% (Admin)

Thames Valley
+25.2% (R&D)
+10.6% (Admin)

Scotland
+40.2% (R&D)
+23.8% (Admin)

Northern Ireland
+51.8% (R&D)
+34% (Admin)

North
+51.6% (R&D)
+33.8% (Admin)

Yorkshire
+51% (R&D)
+33.3% (Admin)

Midlands
+47.4% (R&D)
+30.2% (Admin)

East
+34.3% (R&D)
+18.6% (Admin)

London
+17.3% (R&D)
+3.5% (Admin)

Thames Valley
+25.2% (R&D)
+10.6% (Admin)

Scotland
+40.2% (R&D)
+23.8% (Admin)

Northern Ireland
+51.8% (R&D)
+34% (Admin)

North
+51.6% (R&D)
+33.8% (Admin)

Yorkshire
+51% (R&D)
+33.3% (Admin)

Midlands
+47.4% (R&D)
+30.2% (Admin)

East
+34.3% (R&D)
+18.6% (Admin)

London
+17.3% (R&D)
+3.5% (Admin)

Thames Valley
+25.2% (R&D)
+10.6% (Admin)
Our research provides an update on the trajectory of dementia and highlights the significant effects of dementia research on the UK economy. The dementia prevalence and carer projections (across different types of dementia) to 2040, together with the estimation of the lifetime risk of developing dementia or being a carer, highlight the significant number of people who are likely to be impacted by dementia. This should put the discussion around dementia policy high in political agendas. Particularly, policies addressing the unmet needs of people living with dementia and a framework supporting informal carers both mentally and financially should be prioritised by governments.

In addition, the economic impact assessment reveals that dementia research has positive effect on the UK economy. Specifically, the direct, indirect, and induced benefits, which are expressed both in terms, of jobs and value created in the economy and other sectors of dementia’s research supply chain, are positive and significant. Also, the forecasts from now to 2040 are very promising and show that every £1 invested in dementia research will provide on average £2.91 of economic benefits. Accordingly, the number of jobs and gross value added resulting from dementia research will be increased. These could be even higher if the government increase funding for dementia and effective treatments are developed.

Finally, salaries related to dementia research jobs cause a positive impact to the regional economies in the UK, as they are much higher compared to the average salaries in these regions, and thus have the potential to tackle inequalities across the UK.

In conclusion, increased investment in dementia research and clinical trials has the potential to improve the lives of those affected by dementia but will also facilitate long-term economic growth and stability in the UK.
References


Dementia UK, 2023a. What is dementia? Dementia UK. Available at: https://www.dementiauk.org/about-dementia/dementia-information/what-is-dementia/ [Accessed 27 Apr. 2023].


Freeman, G., 2022. Written questions and answers - Written questions, answers and statements - UK Parliament. [online] Available at: https://questions-statements.parliament.uk/written-questions/detail/2021-12-16/94366 [Accessed 13 Jun. 2023].


Appendix

FIGURES

FIGURE A1: Number of phase 3 clinical trials for dementia in the UK and worldwide.

FIGURE A2: Shares of the UK number of phase 3 clinical trials and UK participants for dementia in the UK and worldwide.
FIGURE A3: Percentage of the funder type in phase 3 clinical trials for dementia in the UK and worldwide.

FIGURE A4: Average number of phase 3 clinical trial sites.
FIGURE A5: Number of phase 3 clinical trials for AD in the UK and worldwide.

FIGURE A6: Percentage of the funder type in phase 3 clinical trials for AD in the UK and worldwide.
FIGURE A7: Number of phase 3 clinical trials for Vascular Dementia in the UK and worldwide.

FIGURE A8: Percentage of the funder type in phase 3 clinical trials for Vascular Dementia in the UK and worldwide.
FIGURE A9: Number of phase 3 clinical trials for Frontotemporal Dementia in the UK and worldwide.

FIGURE A10: Percentage of the funder type in phase 3 clinical trials for Frontotemporal Dementia in the UK and worldwide.
FIGURE A11: Number of phase 3 clinical trials for Lewy Body Dementia in the UK and worldwide.

FIGURE A12: Percentage of the funder type in phase 3 clinical trials for Lewy Body Dementia in the UK and worldwide.
FIGURE A13: Number of UK patients who could have access to global phase 3 clinical trials for dementia.

<table>
<thead>
<tr>
<th>Access to 191 global Phase 3 CTs - Alzheimer’s Disease</th>
<th>Access to 18 global Phase 3 CTs - Vascular</th>
<th>Access to 9 global Phase 3 CTs - Frontotemporal</th>
<th>Access to 6 global Phase 3 CTs - Lewy Body</th>
<th>All global phase 3 CTs for 4 types of dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>11,059</td>
<td>878</td>
<td>163</td>
<td>113</td>
<td>12,213</td>
</tr>
</tbody>
</table>

FIGURE A14: Number of UK patients who could have access to global phase 3 clinical trials for Alzheimer’s Disease.

<table>
<thead>
<tr>
<th>Access to 5 global Phase 3 CTs</th>
<th>Access to 10 global Phase 3 CTs</th>
<th>Access to 15 global Phase 3 CTs</th>
<th>Access to 20 global Phase 3 CTs</th>
<th>Access to 50 global Phase 3 CTs</th>
<th>Access to 100 global Phase 3 CTs</th>
<th>Access to 150 global Phase 3 CTs</th>
<th>Access to 191 global Phase 3 CTs</th>
</tr>
</thead>
<tbody>
<tr>
<td>290</td>
<td>579</td>
<td>869</td>
<td>1,158</td>
<td>2,895</td>
<td>5,790</td>
<td>8,685</td>
<td>11,059</td>
</tr>
</tbody>
</table>
FIGURE A15: Number of UK patients who could have access to global phase 3 clinical trials for Vascular Dementia.

FIGURE A16: Number of UK patients who could have access to global phase 3 clinical trials for Frontotemporal Dementia.
FIGURE A17: Number of UK patients who could have access to global phase 3 clinical trials for Lewy Body Dementia.

TABLE A1: Dementia projection table by sex and disease stage.

<table>
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<tr>
<th></th>
<th>Access to 1 global Phase 3 CTs</th>
<th>Access to 5 global Phase 3 CTs</th>
<th>Access to 6 global Phase 3 CTs</th>
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</thead>
<tbody>
<tr>
<td></td>
<td>2022</td>
<td>2023</td>
<td>2024</td>
</tr>
<tr>
<td>Males and Females</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>942</td>
<td>957</td>
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<tr>
<td>Mild</td>
<td>183</td>
<td>185</td>
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</tr>
<tr>
<td>Moderate</td>
<td>345</td>
<td>350</td>
<td>356</td>
</tr>
<tr>
<td>Severe</td>
<td>415</td>
<td>422</td>
<td>429</td>
</tr>
<tr>
<td>Total</td>
<td>304</td>
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<td>314</td>
</tr>
<tr>
<td>Males</td>
<td>63</td>
<td>64</td>
<td>65</td>
</tr>
<tr>
<td>Moderate</td>
<td>113</td>
<td>115</td>
<td>117</td>
</tr>
<tr>
<td>Severe</td>
<td>128</td>
<td>130</td>
<td>132</td>
</tr>
</tbody>
</table>
### TABLE A2: Dementia projection table by sex and dementia type.

<table>
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<th>2038</th>
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</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
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<td>648</td>
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<tr>
<td><strong>Females</strong></td>
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<td>407</td>
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<td>422</td>
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<td>490</td>
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<tr>
<td><strong>Mild</strong></td>
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<td>129</td>
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<tr>
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<tr>
<td><strong>Severe</strong></td>
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<td>292</td>
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*Note: Values in thousands and rounded.*
TABLE A3: Dementia projection for young onset dementia.

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<td><strong>Female</strong></td>
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</table>

Note: Values in thousands and rounded.

TABLE A4: Dementia projection for dementia in 65 years olds and over.

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<th>2038</th>
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</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td>887</td>
<td>902</td>
<td>918</td>
<td>934</td>
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</tr>
<tr>
<td><strong>Male</strong></td>
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<td>287</td>
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<td>304</td>
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<tr>
<td><strong>Female</strong></td>
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<td>631</td>
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<td>791</td>
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<td>198</td>
<td>199</td>
<td>200</td>
</tr>
<tr>
<td><strong>Moderate</strong></td>
<td>326</td>
<td>332</td>
<td>338</td>
<td>344</td>
<td>350</td>
<td>357</td>
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</table>
### TABLE A5: Variables and data sources used for the economic impact assessment.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Value</th>
<th>Source</th>
</tr>
</thead>
<tbody>
<tr>
<td>Public dementia research investment (2019/2020)</td>
<td>£104,700,000</td>
<td>Written questions and answers - Written questions, answers and statements - UK Parliament (Freeman, 2022)</td>
</tr>
<tr>
<td>Private sector (incl. charities) share of dementia research industry</td>
<td>£99,465,000</td>
<td>Key stats</td>
</tr>
<tr>
<td>Alzheimer’s Research UK share of dementia research industry</td>
<td>19%</td>
<td>Our promise to you - Alzheimer's Research UK (alzheimersresearchuk.org)</td>
</tr>
<tr>
<td>Full time salaries</td>
<td>Researcher: £46,665</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Admin: £41,189</td>
<td></td>
</tr>
<tr>
<td>Employment shares</td>
<td>79% researchers 21% admin</td>
<td>Research and development spending - House of Commons Library (parliament.uk)</td>
</tr>
</tbody>
</table>
### Salary expenditure proportion

<table>
<thead>
<tr>
<th>Salary expenditure proportion</th>
<th>58.1%</th>
<th>Authors’ calculations</th>
</tr>
</thead>
</table>

### Working hours per year

<table>
<thead>
<tr>
<th>Working hours per year</th>
<th>1738</th>
<th><em>Average actual weekly hours of work for full-time workers (seasonally adjusted)</em> - Office for National Statistics (ons.gov.uk)</th>
</tr>
</thead>
</table>

### GVA per FTE

<table>
<thead>
<tr>
<th>GVA per FTE</th>
<th>Researcher: £120,788 Admin: £50,347</th>
<th><em>Labour productivity by industry division</em> - Office for National Statistics (ons.gov.uk)</th>
</tr>
</thead>
</table>

### FTE multipliers

<table>
<thead>
<tr>
<th>FTE multipliers</th>
<th>Type 1: 1.49 (admin)</th>
<th>Type 1: 2.58 (researcher)</th>
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</thead>
</table>

### GVA multipliers

<table>
<thead>
<tr>
<th>GVA multipliers</th>
<th>Type 1: 1.58 (admin)</th>
<th>Type 1: 1.70 (researcher)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 2: 1.82 (admin)</td>
<td>2.01 (researcher)</td>
<td><em>UK input-output analytical tables - product by product</em> - Office for National Statistics (ons.gov.uk), Supply, Use and Input-Output Tables: 1998-2019 - gov.scot (<a href="http://www.gov.scot">www.gov.scot</a>) and authors’ calculations</td>
</tr>
</tbody>
</table>

### TABLE A6: Methods and formulas used for the economic impact assessment.

<table>
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<tr>
<th>Variable</th>
<th>Method</th>
</tr>
</thead>
<tbody>
<tr>
<td>Salary expenditure proportion</td>
<td>Dementia investment / (weighted average salary * number of employees)</td>
</tr>
<tr>
<td>Working hours per year</td>
<td>48 weeks * 36.2 hours per week</td>
</tr>
<tr>
<td>GVA per FTE</td>
<td>OpH CP (output per hour) for each role * working hours per year (1738)</td>
</tr>
<tr>
<td>Full-time equivalent (FTE)</td>
<td>Direct FTE: <em>Dementia research investment spent on employment</em> &lt;br&gt; [\sum (salary \text{ by role} \times \text{ share of employees by role})]</td>
</tr>
<tr>
<td></td>
<td>Indirect FTE: ((Direct \text{ FTE} \times \text{Type 1 multiplier}) - Direct \text{ FTE})</td>
</tr>
<tr>
<td></td>
<td>Induced FTE: ((Direct \text{ FTE} \times \text{Type 2 multiplier}) - Direct \text{ FTE} - Indirect \text{ FTE})</td>
</tr>
<tr>
<td>Gross value added (GVA)</td>
<td>Direct GVA: (\sum (FTE \text{ by role} \times \text{productivity by role}))</td>
</tr>
<tr>
<td></td>
<td>Indirect GVA: ((Direct \text{ GVA} \times \text{Type 1 multiplier}) - Direct \text{ GVA})</td>
</tr>
<tr>
<td></td>
<td>Induced GVA: ((Direct \text{ GVA} \times \text{Type 2 multiplier}) - Direct \text{ GVA} - Indirect \text{ GVA})</td>
</tr>
<tr>
<td>Benefit-cost ratio (BCR)</td>
<td>BCR: Total Benefits (here are equal to the Aggregate GVA)</td>
</tr>
<tr>
<td>-------------------------------------------------------------</td>
<td>----------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Dementia research investment</strong></td>
<td></td>
</tr>
</tbody>
</table>

Notes: For calculations involving the type 1 and 2 multipliers, we used the average multipliers for jobs in R&D and admin. For obtaining productivity by role, we converted GVA per hour into GVA per FTE.
About us
Founded in 1962 by the Association of the British Pharmaceutical Society, the Office of Health Economics (OHE) is not only the world’s oldest health economics research group, but also one of the most prestigious and influential.

OHE provides market-leading insights and in-depth analyses into health economics & health policy. Our pioneering work informs health care and pharmaceutical decision-making across the globe, enabling clients to think differently and to find alternative solutions to the industry’s most complex problems.

Our mission is to guide and inform the healthcare industry through today’s era of unprecedented change and evolution. We are dedicated to helping policy makers and the pharmaceutical industry make better decisions that ultimately benefit patients, the industry and society as a whole.

OHE. For better healthcare decisions.

Areas of expertise
• Evaluation
• The economics of health care systems
• Health technology assessment (HTA) methodology and approaches
• HTA’s impact on decision making, health care spending and the delivery of care
• Pricing and reimbursement for biologics and pharmaceuticals, including value-based pricing, risk sharing and biosimilars market competition
• The costs of treating, or failing to treat, specific diseases and conditions
• Drivers of, and incentives for, the uptake of pharmaceuticals and prescription medicines
• Competition and incentives for improving the quality and efficiency of health care
• Incentives, dis-incentives, regulation and the costs of R&D for pharmaceuticals and innovation in medicine
• Capturing preferences using patient-reported outcomes measures (PROMs) and time trade-off (TTO) methodology
• Roles of the private and charity sectors in health care and research
• Health and health care statistics