

Dementia Attitudes Monitor

Wave 1 2018



**Alzheimer's
Research
UK**

Make
breakthroughs
possible

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| Foreword

HILARY EVANS, CHIEF EXECUTIVE OF ALZHEIMER’S RESEARCH UK

As the UK’s leading dementia research charity, we identify and fund research that will help us prevent, treat and one day, cure dementia. We rely on public donations to carry out our work, so we know that improving understanding and shaping attitudes towards dementia is critical if we are to make breakthroughs in research possible.

The biennial Dementia Attitudes Monitor sets out to track attitudes towards dementia, shape the action we take and inform government and industry now and in the future.

It is a sad truth that more people are affected by dementia than ever before. As the Monitor has revealed, more than half of people in the UK have had a close friend, family member or someone else they know diagnosed with the condition.

Yet despite growing awareness of dementia, there is still a huge amount of work to be done in terms of improving understanding of the diseases that cause it. This shortfall in understanding means that people may be less likely to take steps to maintain their own brain health, to seek a diagnosis or to support research that has the power to bring about breakthroughs and transform lives.

Wave 1 of the Dementia Attitudes Monitor has identified key messages for Alzheimer’s Research UK and other organisations working in the dementia space to prioritise, as well as the major groups within society that we must work hard to engage. Crucially, it has also revealed that people in the UK are open to learning more about their individual risk of developing dementia and to the concept of very early diagnostic tests, as well as being highly supportive of research into prevention and cure. However, more needs to be done to engage people with how they can personally contribute to ongoing research efforts.

The pages ahead provide a detailed picture of public attitudes towards dementia in the UK, shine a light on unhelpful misconceptions that persist, and highlight the opportunities to break through these misconceptions as we work towards a world free from the fear, harm and heartbreak of dementia.

Hilary Evans



Why do perceptions matter?



“ In the years leading up to my diagnosis there were times when I couldn’t remember where I had put things, why I had done something or even at times where I was. However, I thought it was just a result of me getting older.

When I was first diagnosed with Alzheimer’s disease, I was angry and didn’t want to admit it to others, but after a few months I accepted it because I realised that I had many years of my life left and there were still opportunities open to me. It was soon after my diagnosis that I decided to take part in research and I’m now a participant in a clinical trial which is looking to find a way to slow down or stop the progression of the disease.

This is my way of getting something positive out of this difficult experience. It has given me a new sense of purpose and I was pleased to discover that progress is being made. I also share my experience with the public and I have appeared many times in the media in order to promote a more positive attitude towards people with dementia as well as promoting the importance of research.”

Brenda Whittle



“ In May 2015, my dad was diagnosed with early-onset Alzheimer’s disease at the age of just 52.

I’ve seen how much Alzheimer’s disease can impact not only the person diagnosed but the immediate members of the family. It’s the scariest, most intimidating disease I’ve ever seen and been around.

I’ve learnt a lot about dementia since my dad’s diagnosis and I’ve been shocked by how many people are affected by it. I’ve met lots of hugely supportive people but there are still some who seem sceptical that someone of my dad’s age can have Alzheimer’s and this has to change.

I’m now a fundraiser for Alzheimer’s Research UK, because as well as improving understanding of dementia, I want to do my bit to bring us closer to a cure.”

Zeena Patel



Section 1 | Executive Summary

Background to this research

Alzheimer's Research UK commissioned Ipsos MORI to design and implement the Dementia Attitudes Monitor to measure and track public perceptions, attitudes and behaviours around dementia and dementia research. This report outlines the findings from the first Dementia Attitudes Monitor (Wave 1) which took place between 15 June and 5 July 2018.

Methodology

All interviews were carried out as part of Ipsos MORI's regular face-to-face omnibus survey by Ipsos MORI interviewers in participants' homes, using Computer Assisted Personal Interviewing (CAPI). A total of 2,361 interviews were conducted with adults aged 15 and over in the UK between 15 June and 5 July 2018. The face-to-face omnibus uses a rigorous sampling method to ensure a good geographical spread, using quotas for gender, age, working status and tenure to ensure that the sample is nationally representative.

The overall aim of the research is to act as a catalyst for wider public dialogue around dementia and to be used to inform ongoing charity and government efforts to tackle dementia by tracking public perceptions and attitudes to the condition over time.

Following this first wave, the Dementia Attitudes Monitor will be repeated every two years, addressing both core issues and additional areas of focus that are topical or relevant to ongoing policy work in dementia, and helping to guide future communications and campaigns to ensure they reach the right audiences with the right messages.



Key findings of the research

Overall, the findings show that the public's awareness of dementia is relatively high but pockets of misunderstanding remain to be overcome. Many of these relate to the belief that dementia is an inevitable part of ageing, not a cause of death, with mental but not physical effects, suggesting that dementia may not be regarded as a serious health condition by some parts of society.

This is substantiated by the fact that dementia continues to be most commonly described as 'memory loss', 'forgetfulness' or 'old age'. These findings suggest that more needs to be done to show the breadth of people affected by dementia and the range of symptoms they can experience. Although evidence of stigma was relatively low, improved understanding and knowledge could help to tackle concerns that a minority of people continue to have about talking to people with dementia or sharing a potential future diagnosis beyond their own close family.

For some, dementia is the health condition they fear the most. While some of this fear may be driven by the unknown, our data also show that nearly half of those with experience of dementia fear it more than any other health condition, underlining the profound impact dementia has on both the person affected and those around them. And despite positive developments in public attitudes to the condition and a greater emphasis on a person's ability to live well beyond their diagnosis,

it still remains hard to escape the negativity that the public feels around the condition and its current prognosis, with the emotive language used to describe the condition including "cruel", "depressing", "devastating" and "frightening".

The findings of the Dementia Attitudes Monitor also mirror those of other studies in demonstrating that public knowledge of the risk factors associated with dementia remains low. From a prompted list, just a third of people select dementia as a health condition they can reduce their risk of developing and almost half fail to identify any of the key risk factors that could increase a person's risk of developing dementia. It is plausible that enduring perceptions of dementia as an inevitable part of ageing or not a cause of death, combined with an overall lower public understanding of the physical impact of dementia, contributes to poorer recognition of physical contributors to dementia risk compared to factors like less mental activity, loneliness, depression and stress.

Alzheimer's Research UK has called on the UK government to spearhead dedicated dementia risk reduction and wider brain health campaigns for both the public and health and social care professionals. There is significant opportunity through the review of the government's 2020 Challenge on Dementia to prioritise future dementia risk reduction messaging, and to use these insights, along with others, to ensure that such messaging

is appropriately developed, presented and disseminated.

Most people are keen to learn more in midlife about their own personal risk of developing dementia later in life if doctors could give them this information. Most people are willing to undergo non-invasive tests, such as an eye test, memory test or blood test, to help doctors make an early diagnosis and 85% of the public would be willing to take a test to tell them if they were in the early stages of a disease like Alzheimer's, even before symptoms showed.

However, there are pockets of people who would prefer not to know about their risk or would not be willing to take early diagnostic tests – mainly older age groups (55 and above), those who spent less time in formal education and those who have no experience of dementia. These people generally feel

that there is a lack of effective treatments for the diseases that cause dementia and see no value in receiving a formal diagnosis.

Overall, the findings do show a strong appetite from the public to know more about their brain health, with younger generations more open to innovative techniques, such as apps that monitor day-to-day life, designed to support an early diagnosis of diseases like Alzheimer's in future. Although a lack of available effective preventions and treatments may be discouraging some, overall there is strong support for people with dementia being given a formal diagnosis by a doctor, in order to allow them to plan for their future and access treatments that can help.

With dementia research moving to a stage where detecting those most at risk at an early stage will be essential for the development and delivery of future treatments, these results are very promising for the dementia research and healthcare communities. The findings will be valuable to inform the work of initiatives like the Alzheimer's Research UK Dementia Access Taskforce, which brings together charity, government and industry to ensure that people with dementia can get future treatments quickly, including scoping the barriers and opportunities to establish earlier diagnosis and shift towards molecular-based diagnosis and risk profiling.

Despite a lack of clarity about the current treatments available for dementia and how effective they are, the public shows support for research into cure and prevention. This is more than twice as common as answers relating to research into new symptomatic treatments or ways to improve quality of life of those affected now. While all are important avenues of research and have the potential to make a significant impact to the lives of those living with dementia and their families, the public's research priorities are very much on how dementia is prevented and treated in future.

Despite this, the results show that only half of those who participated would be willing to get involved in medical research for dementia in the future. Willingness to participate in research is lowest among those aged 65 and above – a particularly important age group to engage with research.

The Dementia Attitudes Monitor sets an important baseline for future analysis of trends

in understanding and stigma, and identifies younger people, people with no experience of dementia, and those from black, Asian and minority ethnic (BAME) background groups as those who could gain the most from targeted discussions about the condition.

Lower awareness of dementia risk and lack of understanding of the nature of the condition among BAME communities is indicative of broader challenges reaching this key audience with accessible and appropriate health messaging. However, with the likelihood that some BAME groups may experience higher rates of dementia and that lack of understanding could result in delays to diagnosis and access to services, they constitute an important and rapidly growing section of society to reach. Ensuring

that future campaigns, messaging and support are culturally sensitive and informed by input from BAME communities will help to ensure that these groups have the opportunity to benefit from ongoing positive developments in dementia research.

While there are clear positive steps in awareness and education around dementia, the Dementia Attitudes Monitor highlights key areas that charities, government and dementia-interested organisations must continue to work hard to address. As research develops at pace, public understanding and engagement with such progress must develop in tandem to enable everyone to benefit from such breakthroughs.



Section 2 | Introduction

2.1 | BACKGROUND AND OBJECTIVES

It is estimated that over 850,000 people in the UK are currently living with dementia¹ and, with an ageing population, it is predicted that this figure will increase to over one million people by 2025².

The diseases that cause dementia already have an economic impact of more than £26 billion a year, which is more than cancer and heart disease combined, but this figure is expected to more than double in the next 25 years to £55 billion in 2040³. In 2017, dementia became the leading cause of death in the UK, with 76,090 people dying from Alzheimer’s disease and other forms of dementia, compared to 66,341 due to heart disease⁴.

Ipsos MORI research for the Department of Health has shown that while cancer and obesity continue to be perceived by the public as the biggest health problems facing people today, awareness of dementia is increasing⁵. Furthermore, among the over 50s, ‘dementia/ Alzheimer’s disease’ is cited as the biggest perceived health problem facing older people⁶.

Recent polling for Alzheimer’s Research UK⁷ also highlighted dementia as one of the top three health conditions spontaneously named by UK adults as requiring NHS prioritisation in terms of resources, innovation and funding in the next 10 years and showed that one in four UK adults believe dementia is the biggest health challenge facing the NHS in the coming 70 years.

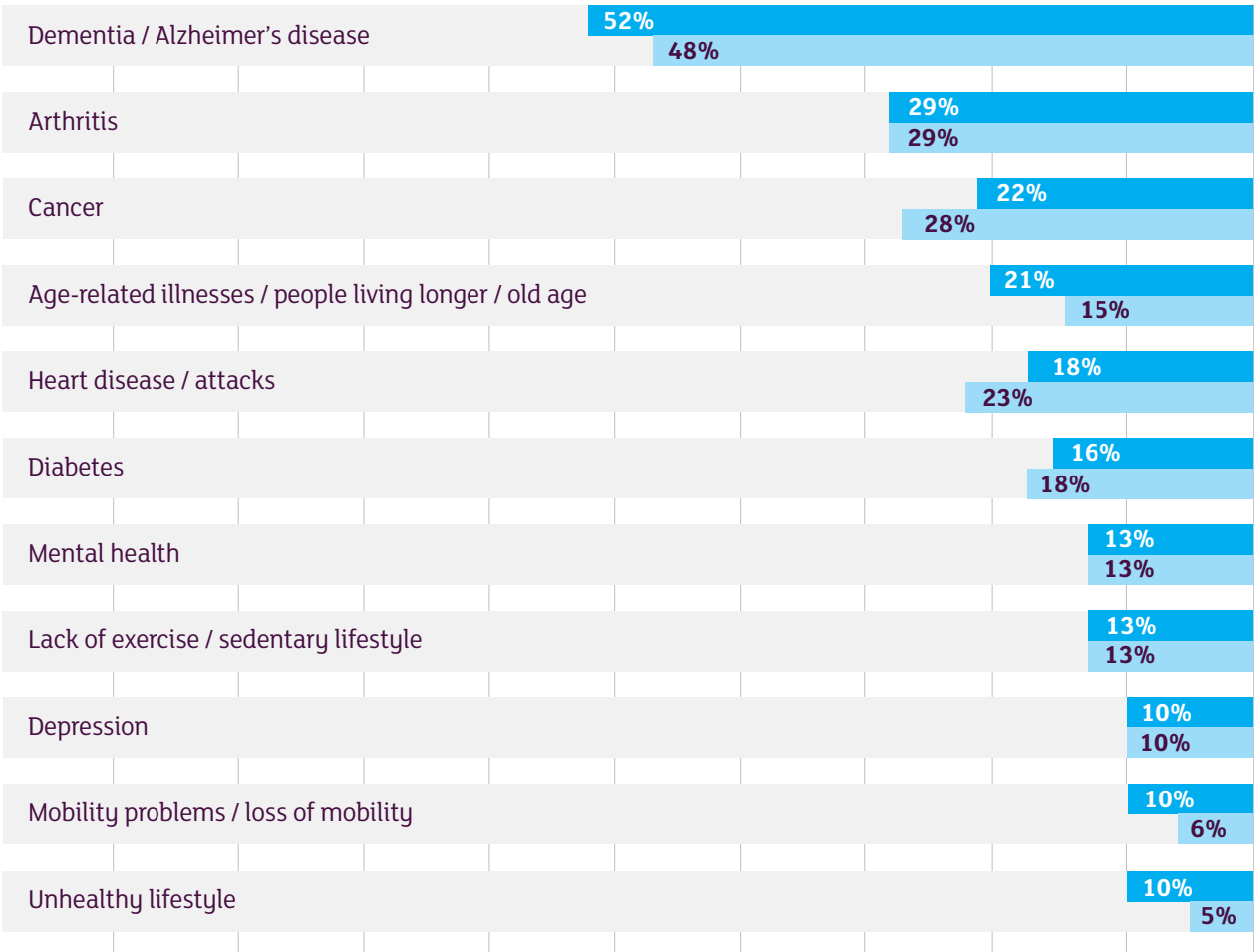
Alzheimer’s Research UK is the UK’s leading dementia research charity, dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure. A core objective of the charity is to challenge the way people perceive the condition, to overturn outdated views, and to engage the public with the potential of research to change the lives of people with dementia.

To allow Alzheimer’s Research UK to measure and track public perception, attitudes and behaviours around dementia, the charity commissioned Ipsos MORI to design and implement a new, UK-wide Dementia Attitudes Monitor. The overall aim of the Monitor is to act as a catalyst for wider public dialogue around dementia and inform and shape campaigns and policy work being driven by the charity and beyond.

This report outlines the findings from the first (2018) wave of the Dementia Attitudes Monitor, which captures attitudes across different groups within the UK population aged 15 years and over, including different age groups, gender, ethnic groups, geographic location, as well as those directly and indirectly affected by dementia. After this initial research, the Monitor will be used to track attitudes towards dementia over time, complementing ad hoc polling conducted by Alzheimer’s Research UK, the UK government and other dementia-related organisations.



What are the biggest health problems facing older people today? What else?



Base: Adults 50+ in England 2017, 3 January 2017 - 19 February 2017 (755), 4 January 2016 - 21 February 2016 (759) This question was unprompted, meaning participants were not presented with a list of potential answer codes when answering this question. Participants are able to give more than one answer to this question.
Source: Ipsos MORI/DH Health, Ageing and Support Tracker

2.2 | THE STRUCTURE OF THE REPORT

The first chapter of this report is the introduction, which sets out the background and the objectives of the survey, followed by chapters 2 – 6, which describe the findings in detail. Details of the methodology, notes about how to interpret the data, the statistical reliability of the data, a guide to the social classifications referred to in this report, and the questionnaire (including topline results) are included in the appendices.

This report also includes an executive summary at the start, which provides an overview of the key findings from the survey.





Section 3 | Awareness & understanding

This chapter explores people's awareness of dementia, in general, and specifically Alzheimer's disease – the most common cause of dementia. It also examines the public's understanding of the effects of dementia on a person's health. To set the findings in context, the first section in this chapter outlines the proportion of participants who know someone who has been diagnosed as having a form of dementia.

2.3 | NOTE ABOUT PRESENTATION AND INTERPRETATION OF THE DATA

This report presents the data from the first Dementia Attitudes Monitor in the series, conducted between 15 June and 5 July 2018.

This report comments on differences in the data between different subgroups within the total sample, for example differences in views between men and women. A difference has to be of a certain size in order to be statistically significant and only differences that are statistically significant at the 95% confidence level are commented on in this report.

As a rule, only subgroups comprising 100 or more participants are commented on in this report (unless specific exceptions are highlighted). It should be noted, however, that the smaller the size of the subgroup, the

less we can rely on the survey estimates to be truly representative of the population as a whole. Findings for groups with as few as 100 participants can be subject to confidence intervals of +/-10% (please see appendix 8.3 for more details).

In addition to being statistically significant, only subgroup differences that are interesting and relevant to the question being analysed are commented on in the report.

Survey participants are permitted to give a 'don't know' answer to some questions and these responses are included in the analysis.

Where percentages do not sum to 100%, this may be due to computer rounding, the exclusion of 'don't know' categories, or participants being able to give multiple answers to the same question. Throughout the report an asterisk (*) denotes any value of less than half of 1% but greater than 0%.

Where this report refers to the proportion of those who 'agree', this is an aggregate sum – for example, of those who say they 'strongly agree' and those who say they 'tend to agree'. In turn, 'disagreement' figures refer to an aggregate sum – for example, of those who say they 'strongly disagree' and those who say they 'tend to disagree'. The same applies to questions with scales for 'willing'/'reluctant' and 'effective'/'not effective'.

It is worth bearing in mind that this survey deals with public perceptions at the time of the survey rather than facts; these perceptions may or may not accurately reflect treatments and medical research being delivered by organisations providing care and support for individuals living with dementia.



3.1 | KNOWING SOMEONE WITH DEMENTIA

Half of the people (52%) who took part in the Dementia Attitudes Monitor know someone who has been diagnosed as having a form of dementia, such as Alzheimer's disease. Typically, this is a close friend or family member (42%) such as a grandparent (15%) or parent (11%), as shown in the chart on page 14.

Given the age profile of those with dementia it is perhaps not surprising to find that young people aged 15-24 are more likely than older people to say that no-one close to them has received a dementia diagnosis (57%, compared with 40% of those aged 25 or over). However, one third (33%) of young people still reporting an experience of dementia shows the wide-reaching impact of the condition across all generations.

People from black, Asian and minority ethnic backgrounds are also more likely than white people to say that no-one close to them has been diagnosed (58%, compared with 40% white). However, it is important to note that this finding could reflect the younger age profile of black, Asian and minority ethnic participants in the research, with younger people, as noted above, less likely to know someone who has been diagnosed with dementia.

The Dementia Attitudes Monitor highlighted people in higher social grades⁸ as being more likely to say they know someone with dementia than people who are less affluent (63% in social grades AB, compared with 46% in social grades DE). This is also true of women (54%, compared with 50% of men) and those in the highest income quartile (60% of those earning £30,000 or more, compared with 50% of those earning between £11,500 and £24,999).

Throughout the report, where attitudes or experiences differ, comparisons are made between people who know someone with dementia and those who do not. This is in line with previous research⁹ that has shown that the experience of knowing someone with dementia is key to understanding attitudes to dementia.

3.2 | PERCEPTION OF DEMENTIA AND ALZHEIMER'S DISEASE

Dementia is an umbrella term for a set of symptoms that affect cognitive function, such as memory loss, confusion and personality change, which gradually worsen over time.

Alzheimer's disease is the most common cause of dementia, accounting for about two thirds of all dementia cases. As part of the Dementia Attitudes Monitor, the research set out to understand whether public perceptions of the term 'dementia' differ from those of 'Alzheimer's disease'.

Has a close friend, a member of your family or someone else you know been diagnosed as having a form of dementia such as Alzheimer's disease?

Response	Percentage
No, no-one close to me has been diagnosed	43%
Yes, grandparent(s)	15%
Yes, parent(s) (inc. step)	11%
Yes, other close family member(s)	8%
Yes, other family member(s)	7%
Yes, a person other than those listed	6%
Yes, close friend(s)	5%
Yes, other friend(s)	5%
Yes, neighbour(s) / someone from local community	4%
Yes, partner or spouse	1%
Yes, brother / sister(s) (inc. step)	1%
Yes, work colleague(s) / former colleague(s)	1%
Don't know	5%
Prefer not to say	1%
Yes, myself	*

52% of respondents know someone who has been diagnosed with some form of dementia

Base: Adults aged 15+ in the UK (2,361)

However, when asked to think about Alzheimer's disease, people were less likely to focus on age, than when discussing dementia, and more likely to describe the general effects of the condition, such as behavioural changes, frailty and loss of independence.



It follows that older people, who are more likely to know someone with dementia, tend to give a wider range of responses. While two-thirds of 15-24 year olds (66%) mention memory loss or forgetfulness, just 44% of people in the 65 or over age range do so. This group is more likely than 15-24 year olds to focus on the emotional impact of dementia (24% provide an emotional response, compared with six per cent of 15-24 year olds). Older people are also more likely to highlight the general symptoms of dementia as opposed to highlighting the link with age, which is a focus of young people.

Public knowledge of the effects of dementia on a person's brain vary by age, ethnicity and experience of knowing someone with dementia:

- Around one in five people aged 15-24 (21%) and 25-34 (22%) say they do not know what happens in a person's brain when they get dementia, compared with one in ten people aged 55-64 (10%) and 65 or over (12%).
- Around one in five people from black, Asian and minority ethnic backgrounds (22%) say they do not know, compared with 14% of those who are white.
- People who have no experience of dementia are more likely to say they do not know what happens in a person's brain, compared with those who know someone with dementia (18% and 12%, respectively).

The variation in response by age, ethnicity and knowledge of dementia is also played out when the public is asked to consider the impact of Alzheimer's disease on the brain.

3.4 | AWARENESS OF THE PHYSICAL AND MENTAL EFFECTS OF DEMENTIA

Dementia can have a physical, as well as mental, impact on the human body, particularly as the symptoms progress. To measure awareness, people were asked the extent to which they agree or disagree with two statements, detailed in the Chart below.

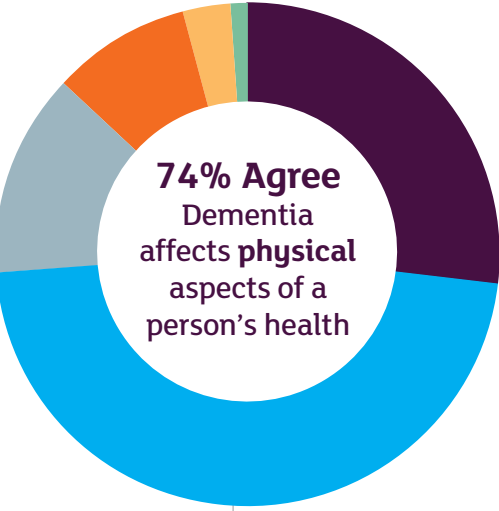
The vast majority (93%) agree that 'Dementia affects mental aspects of a person's health'. Only two per cent disagree and five per cent are unsure either way. However, there are lower levels of awareness of the physical effects of dementia. Just three quarters of adults in the UK (74%) agree that 'Dementia affects physical aspects of a person's health', while around one in ten (12%) disagree.

Table 3.1: The impact of dementia on physical health

'Dementia affects physical aspects of a person's health'				
	Base	Agree	Neither agree nor disagree	Disagree
TOTAL	(2,361)	74%	13%	12%
Gender				
Female	(1,238)	76%	12%	11%
Male	(1,123)	71%	14%	13%
Ethnicity				
White	(1,794)	75%	12%	11%
BAME	(543)	63%	19%	15%
Experience of dementia				
Any experience	(1,163)	79%	10%	10%
No experience	(1,174)	68%	16%	14%

For each statement, please tell me the extent to which you agree or disagree

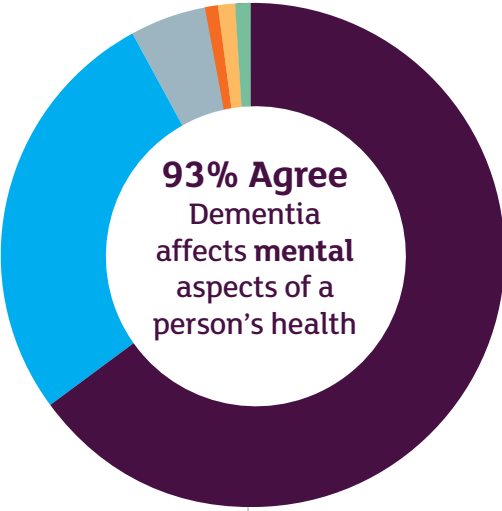
Dementia affects physical aspects of a person's health



- 27% Strongly agree
- 47% Tend to agree
- 13% Neither agree nor disagree
- 9% Tend to disagree
- 3% Strongly disagree
- 1% Don't know

Base: Adults 15+ in UK (2,361)

Dementia affects mental aspects of a person's health



- 66% Strongly agree
- 27% Tend to agree
- 5% Neither agree nor disagree
- 1% Tend to disagree
- 1% Strongly disagree
- 1% Don't know

Awareness of the possible impact on physical health varies by gender, ethnicity and experience of knowing someone with dementia. Men are less likely to agree that dementia affects the physical aspects of a person's life than women, as are people from a black, Asian and minority ethnic (BAME) group compared to those from a white background, and people who don't know someone with dementia.

3.5 | DEMENTIA AS A CAUSE OF DEATH

Dementia is a progressive illness meaning that symptoms worsen over time. Often people with late-stage dementia lose their physical abilities including walking and sitting, and become at increased risk of contracting infections, especially pneumonia. As noted in the introduction to this report, dementia is now the leading cause of death in the UK.



To explore the public's knowledge of dementia, they were asked the extent to which they agree or disagree with the statement 'Dementia is a cause of death'. Just half of the public (51%) correctly identify that dementia can be a cause of death, 25% disagree this is the case and 22% are unsure either way (say neither agree nor disagree), as shown in the chart below.

The proportion of people across subgroups who agree that 'Dementia is a cause of death' is largely consistent, the only variation is by ethnicity and contact with people living with dementia:

- Around half (53%) of those from a white ethnic group identify that 'Dementia is a cause of death', compared with 40% of those from a black, Asian and minority ethnic group.
- People with experience of dementia are more likely to agree that 'Dementia is a cause of death', compared with those who have no contact with people living with dementia (56%, compared with 46%).



3.6 | DEMENTIA AS AN INEVITABLE PART OF GETTING OLDER

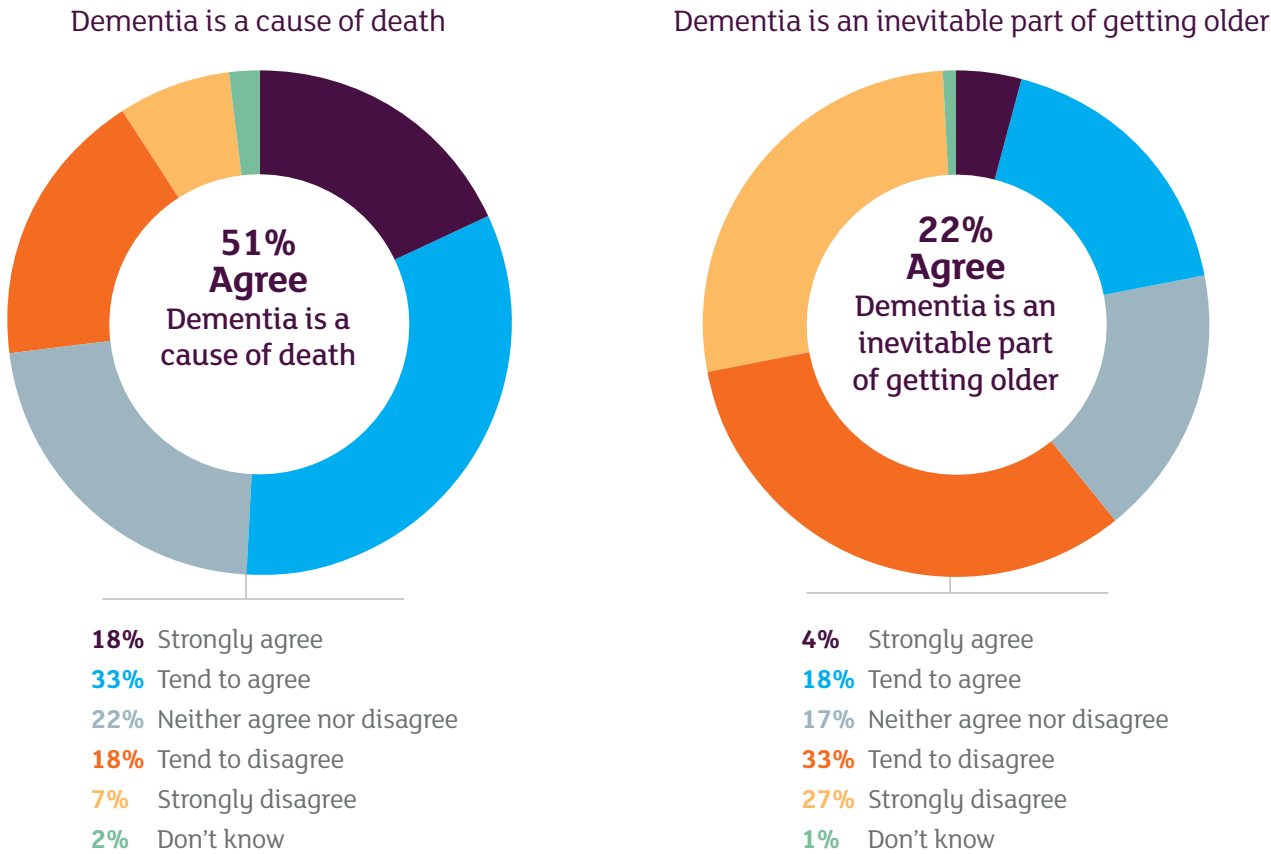
To further explore understanding of dementia the public were asked the extent to which they agree or disagree with the statement 'Dementia is an inevitable part of getting older'. While three in five people (60%) correctly disagree that dementia is an inevitable part of getting older, one in five adults (22%) incorrectly agree with the statement. A further 17% are unsure either way.

While it is reassuring to find that only one in five people feel that dementia is an inevitable part of ageing, a figure that is in line with the MSD 2018 European Attitudes to Alzheimer's research survey¹², it also suggests that further work is needed to tackle this enduring misperception. Responses to further questions in the Dementia Attitudes Monitor show that those who agree that dementia is an inevitable part of ageing are also more likely to disagree that there is value in a formal diagnosis of dementia and to believe that current treatments are effective enough. Campaigns to challenge this belief may therefore enable more open debate about the value of future research, as well as improving the likelihood that someone experiencing early symptoms would visit their doctor.

Messaging campaigns to tackle this misconception would benefit from being targeted at the key groups who are more likely to agree with the misconception that dementia is an inevitable part of getting older, including:

- Young adults: over a quarter (27%) of people aged 15-24 years agree that 'dementia is an inevitable part of getting older', compared with 19% of those aged 55-64 years.
- People from black, Asian and minority ethnic backgrounds: a third (33%) agree, compared with 21% of those who are white.
- People in working class social grades DE: a third (32%) view dementia as a normal part of ageing, compared with 12% of people in middle class social grades AB¹³.
- People with no formal qualifications: over a third (35%) agree with the statement, compared with just 14% who are educated to degree level or higher.

For each statement, please tell me the extent to which you agree or disagree



Base: Adults 15+ in UK without a dementia diagnosis (2,354)



Section 4 | Stigma

Research has suggested that the social stigma surrounding dementia is a concern in terms of the provision of dementia care, an obstacle to the early diagnosis and quality of life of people with dementia and a barrier to engagement with dementia research¹⁴. In recent Ipsos MORI research for the Department of Health, when asked who they would speak to if they were worried about memory loss, more people say they would speak to a family member than would speak to their own GP¹⁵.

This chapter explores the public’s willingness to engage with people living with dementia and their own reaction to the possibility of being diagnosed with dementia in the future.

4.1 | ENGAGING WITH PEOPLE WITH DEMENTIA

Just over one in five people (22%) agree that *‘I would find it hard to talk to someone who has dementia’*, while around three in five people (62%) disagree. As shown in the chart on the next page, 15% are unsure either way .

Research conducted for Public Health England in 2015, through the NatCen Social Research British Social Attitudes Survey, reported that 27% of people agree with the statement ‘I would find it hard to talk to someone who has dementia’, and 57% would disagree. Although the two studies are not directly comparable, the findings from the Dementia Attitudes Monitor 2018 suggest a slight drop in the proportion of people who agree with this statement, suggesting that public acceptability and awareness around dementia may have improved in the last few years.

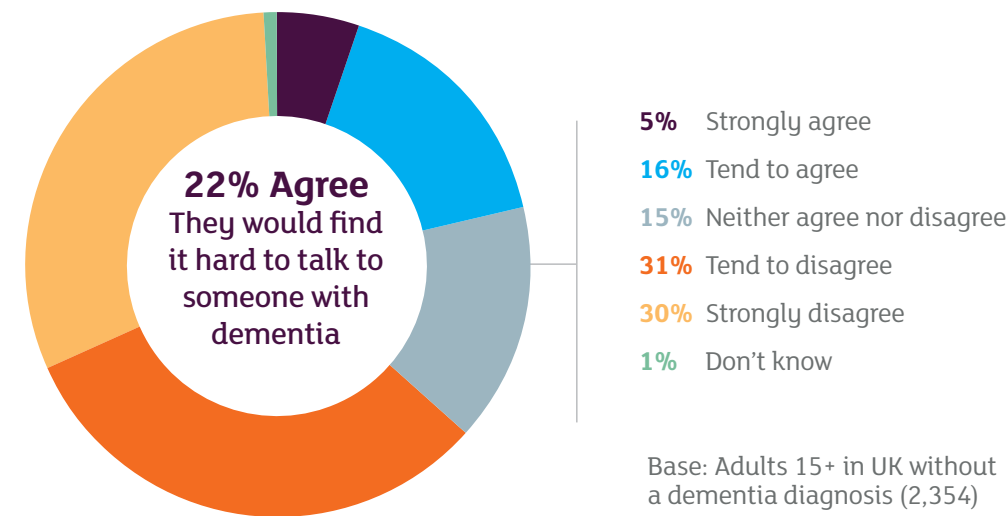
Several characteristics are associated with the view that talking to someone with dementia is hard, such as gender and age. Here, and in the British Social Attitudes Survey, men are highlighted as being more likely than women to say they would find it hard to speak to someone with dementia (26%, compared with 17%). The lower the age the more likely people are to feel concerned about talking to someone with dementia; 27% of those aged 15-34 agree with the statement, compared with 19% of people aged 35 or over.

By ethnicity, 30% of people from black, Asian and minority ethnic backgrounds agree *‘I would find it hard to talk to someone who has dementia’*, compared with 21% of people who are white.

The views of young people and those from black, Asian and minority ethnic backgrounds may be related to them having reported little or no experience of dementia: approaching a quarter (23%) of those who do not know anyone with dementia agree with the statement *‘I would find it hard to talk to someone who has dementia’*, 22% are unsure and just over half (54%) disagree. By contrast, 69% of people who know someone with dementia disagree with the statement.



Please tell me the extent to which you agree or disagree with the statement *‘I would find it hard to talk to someone who has dementia’*



4.2 | BEING PERSONALLY AFFECTED BY DEMENTIA

Developing dementia

Concern regarding developing dementia in the future is high: two in five people agree with the statement *‘Dementia is the health condition I fear most about getting in the future’*, (42%, compared with 36% who disagree). One in five people (21%) neither agree nor disagree, as shown in the chart on page 24¹⁶.

Again, women, older people and, in general, those with experience of dementia are more likely to share concerns about developing dementia:

- Half of people aged 65 or over (51%) agree that dementia is the condition they fear most, compared with 37% of people aged 15-24 years.
- Women are more likely to agree with the statement than men (47%, compared with 37%).
- Nearly half (47%) of people with experience of dementia are likely to agree that dementia is the health condition they fear most, suggesting that the difficulties of living with dementia, or the lack of available treatments, make a lasting impression on those who witness the condition.
- Over a third (36%) of people with no experience of dementia still cite dementia as their most feared condition.

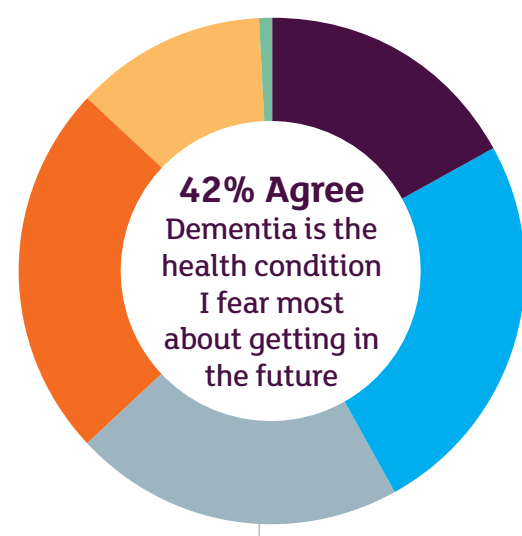
Telling others

People were asked to think about how they would feel if they were diagnosed with dementia and had to tell someone outside of their own family. Most (59%) agree that they would *‘feel comfortable telling people outside my close family’*. However, possibly reflecting a perceived stigma surrounding dementia, a quarter (23%) disagree¹⁷.



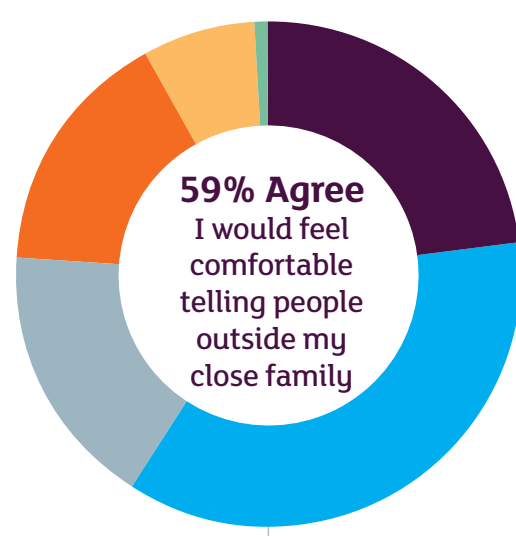
For each statement, please tell me the extent to which you agree or disagree

Dementia is the health condition I fear most about getting in the future



17% Strongly agree
25% Tend to agree
21% Neither agree nor disagree
24% Tend to disagree
12% Strongly disagree
1% Don't know

If I was diagnosed with dementia, I would feel comfortable telling people outside my close family



23% Strongly agree
36% Tend to agree
17% Neither agree nor disagree
16% Tend to disagree
7% Strongly disagree
1% Don't know

Base: Adults 15+ in UK without a dementia diagnosis (2,354)

Attitudes towards telling others about a dementia diagnosis are largely consistent across the subgroups, apart from age and experience of the condition, with younger people and those with no experience of dementia less likely to feel comfortable telling people outside of their family:

- Only half (52%) of people aged 15-34 years agree with the statement 'If I was diagnosed with dementia, I would feel comfortable telling people outside my close family', compared with 62% of people aged 35 or over;
- Similarly, just over half (54%) of people with no experience of the condition would feel comfortable with telling others about their own dementia diagnosis, compared with 64% of those who have known someone with dementia.

Since 2012, face-to-face and online Dementia Friends training has helped over 2.5 million people learn more about dementia and the small ways in which they can help people living with the condition. Initiatives to engage the public with the lived experience of dementia, such as Alzheimer's Research UK's 'A Walk Through Dementia' virtual reality experience and ongoing educational programmes for younger people, are working to increase understanding and challenge stigma around dementia.

Maximising the reach of such programmes, including within hard-to-reach communities, will help to increase knowledge and empathy for those affected and will provide an opportunity for people to think about how they would engage positively with someone with dementia in their own family or community.

Section 5 | Risk

This chapter addresses a key objective of the research; to measure people's awareness of risk factors around dementia. It explores understanding of risk factors relating to several health conditions, including dementia, and perceptions of what can be done to reduce the chances of developing those conditions.

5.1 | REDUCING THE RISK OF DEVELOPING HEALTH CONDITIONS

Studies have shown that public knowledge of risk factors for dementia is lower than knowledge of symptoms¹⁸. Recent public health promotions, such as Public Health England's One You campaign, are designed to help people understand that making better choices when it comes to eating, drinking and smoking can help to prevent diseases such as type 2 diabetes, cancer and heart disease, and reduce the risk of dementia.

The Dementia Attitudes Monitor presented adults (aged 15+) with a list of five health conditions and asked them to consider which, if any, it is possible for people to reduce their risk of developing. The majority of people identify diabetes and heart disease (81% and 77%, respectively). Three in five (60%) believe that people can reduce their risk of having a stroke, and just over half (52%) say the same about cancer.

People are less likely to believe that it's possible to reduce the risk of developing dementia than the four other health conditions. As shown in the chart on the following page, just a third (34%) of people select dementia as a health condition they can reduce the risk of developing.

Despite being substantially lower than risk awareness of other health conditions, the proportion of people who think they can reduce their risk of developing dementia is higher in the 2018 Dementia Attitudes Monitor, compared with polling from Alzheimer's Research UK in 2016¹⁹, which showed that only 25%

of UK adults were aware there was anything they could do to reduce their risk of dementia. Although the two studies are not directly comparable, the findings suggest an increase in awareness of dementia risk over previous years.

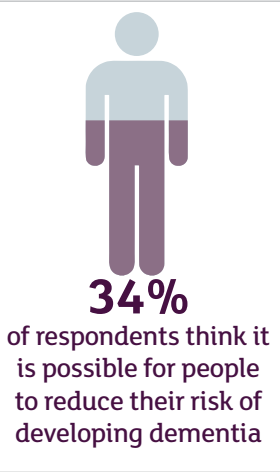
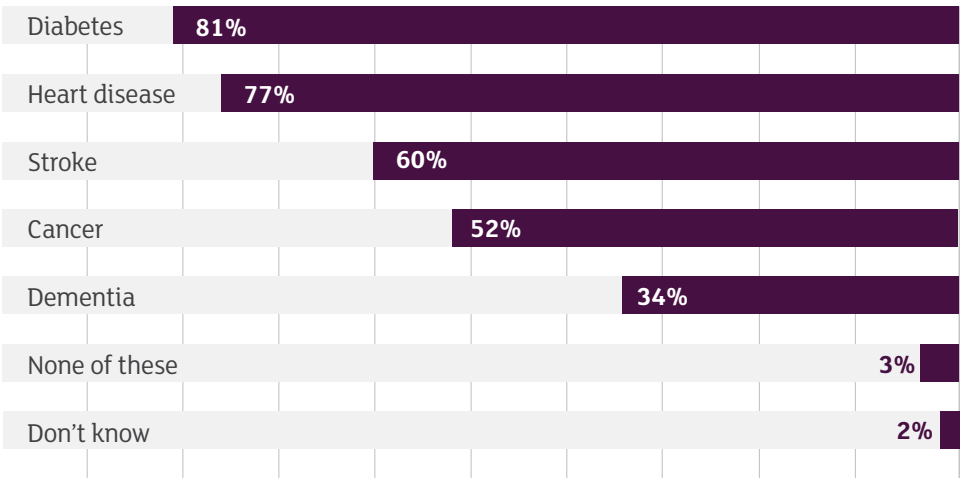


Evidence currently suggests that midlife is a key window of opportunity for dementia risk reduction. Promisingly, those in early midlife (45-54 year olds) had the highest awareness that dementia risk was modifiable (40% compared to 34% for all adults). This is positive as this group is most likely to benefit from interventions that could support positive brain health, and new initiatives like including dementia risk reduction messaging in NHS Health Checks for 40-64 year olds in England, as well as for over 65s, should help to bolster this important message.

Looking specifically at the characteristics of people who are less likely to think that it's possible to reduce the risk of developing dementia: just 29% of people from black, Asian and minority ethnic backgrounds consider it possible to reduce the risk of developing dementia, compared with 35% of adults who describe themselves as white. This is likely to reflect the younger age profile of BAME respondents, as 15-24 year olds of all ethnic backgrounds are less likely to consider it possible to reduce the risk of developing dementia, than all adults (28%; compared with 34%).



Which, if any, of the following health conditions do you think it's possible for people to reduce their risk of developing?



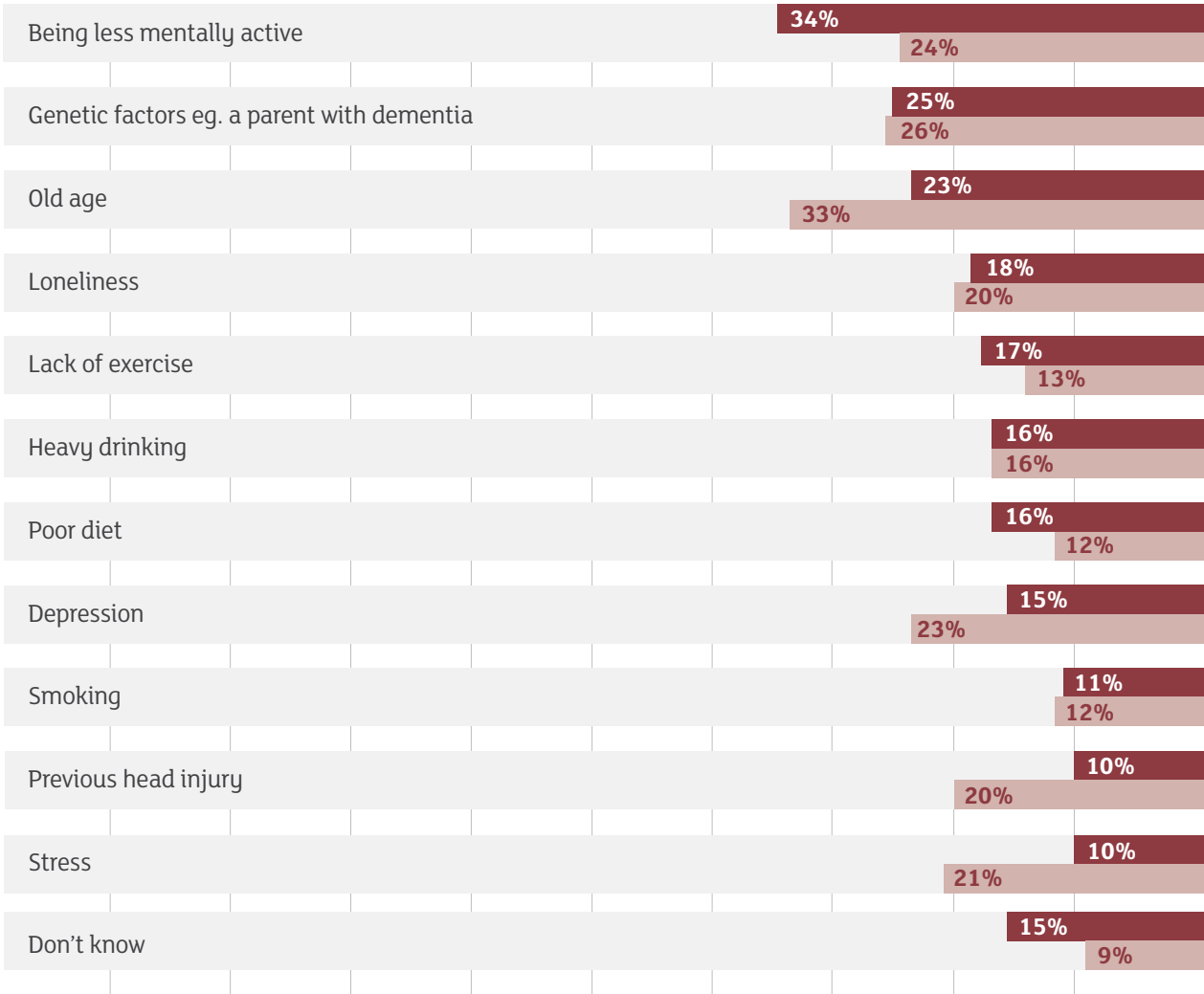
Base: Adults 15+ in the UK (2,361)

People with no formal qualifications (27%) and those educated to GCSE/ equivalent level (30%), are less likely to consider it possible to reduce the risk of developing dementia than those educated to degree level or higher (43%). As are those with no experience of dementia (30%) compared with people who have close friends and family who have been diagnosed with dementia (38%).

5.2 | INCREASING THE RISK OF DEVELOPING DEMENTIA

An individual's risk of developing dementia is made up of different factors such as age, genetics and lifestyle. Recent research has shown that some of the risk factors for Alzheimer's are the same as for cardiovascular disease. For example, controlling high blood pressure and maintaining a healthy weight²⁰.

What, if anything, do you think could increase a person's risk of developing dementia?



■ Spontaneous mention ■ Prompted mention

Base: Adults aged 15+ in the UK (2,361)
Risks mentioned by 10% or more participants at QUY06 listed.

To evaluate people’s awareness of risk factors they were asked to consider what, if anything, could increase a person’s risk of developing dementia. This was initially asked as a spontaneous question and then repeated with a list of possible answers.

In 2015, the British Social Attitudes survey found that one per cent of UK adults could correctly identify seven risk or protective factors for dementia (risk: heavy drinking, genetics, smoking, high blood pressure, depression, diabetes; and protective: physical exercise), with 22% failing to identify any at all. Repeating this question in the Dementia Attitudes Monitor, using the same list of risk factors, again just one per cent of the public correctly identified all seven factors, while approaching half (48%) fail to identify any²¹. Furthermore, the proportion of adults who correctly identify 1-2 risk factors remains the same (43% in both the BSA survey and the Dementia Attitudes Monitor).

Although the two surveys are not directly comparable, this suggests that while there is an increase in general awareness of dementia risk, the public’s understanding of what those risk factors are is not increasing in tandem, in fact it appears to be becoming less clear.

The following groups are less likely to identify any of the seven risk factors:

- People from a black, Asian and minority ethnic background (54%, compared with 47% of people who identify as white).
- Those in social classes DE (56%, compared with 41% of those in social classes AB).

- Those with no experience of dementia (51%, compared with 46% of people with ‘any’ experience).

As shown in the chart on page 27, the Dementia Attitudes Monitor shows that the public’s most common spontaneous response to being asked about the risk factors associated with dementia are ‘being less mentally active’ (34%), ‘genetic factors’ (25%) and ‘old age’ (23%).

When presented with a prompted list the same three risk factors are most commonly mentioned, albeit in reverse order: ‘old age’ (33%), ‘genetic factors’ (26%) and ‘being less mentally active’ (24%). People are more likely to highlight ‘depression’ (23%), ‘stress’ (21%) and ‘a previous head injury’ (20%) when shown a list, than when they were asked to consider possible risk factors spontaneously.

The strongest consistent evidence of lifestyle factors affecting dementia risk is for cardiovascular risk factors such as high blood pressure, smoking, obesity and lack of physical activity²². Although more than one in 10 adults named lifestyle factors such as lack of exercise, heavy drinking, poor diet and smoking, both spontaneously and unprompted, just one in 20 spontaneously identified being overweight and high blood pressure as risk factors for dementia (5% in both cases).

It is plausible that enduring perceptions of dementia as an inevitable part of ageing or not a cause of death, combined with an overall lower public understanding of the physical impact of dementia, contributes to poorer recognition of physical contributors to

dementia risk compared to factors like not keeping mentally active, loneliness, depression and stress.

Lower awareness of dementia risk in certain groups, including those of black, Asian and minority ethnic background and those in working class socio-demographic groups, is indicative of broader challenges reaching these audiences with health messaging. These data show that dementia messaging is no exception to that challenge and that public health messaging should continue to work hard to engage harder-to-reach groups in a way that is sensitive to their personal situations and considers broad variations in health literacy across the population.

Examples of this include Alzheimer’s Research UK’s programme of work that sets out to ensure information about dementia and risk is accessible to those whose first language is not English, by developing non-English language resources in partnership with BAME community groups in the East and West Midlands²³.

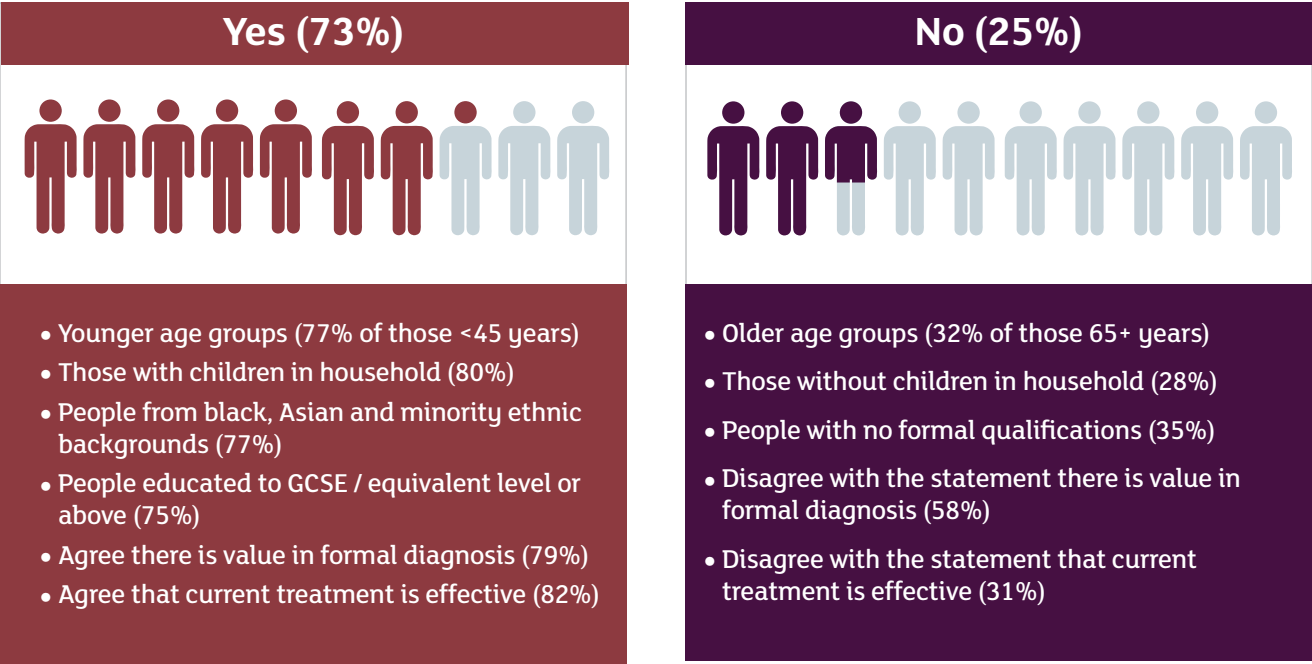
5.3 | PERSONAL RISK OF DEVELOPING DEMENTIA

To further explore attitudes to developing dementia, people were asked whether they would want to know in midlife their personal risk of developing dementia later in life, based on their genetics or lifestyle, if doctors could provide this type of information.

The findings indicate a desire amongst the public to understand their dementia risk as the majority (73%) say they would want to be told by a doctor their own personal risk of developing dementia in later life; 47% say ‘Yes, definitely’ and 26% say ‘Yes, probably’. However, a quarter of people (25%) do not want to know, 11% of whom are definite about this.

The chart below highlights the characteristics of people who say ‘Yes’ (either ‘Yes, definitely’ or ‘Yes, probably’), they would want to know this information, and those who would not (say ‘No, probably not’ or ‘No, definitely not’).

If doctors were able to give you information in midlife about your personal risk of developing dementia in later life, would you want / have wanted to know or not?



Base: Adults aged 15+ in the UK (2,361) ‘Yes’ is a combination of answers given to ‘Yes, definitely’ or ‘Yes, probably’. ‘No’ is a combination of ‘No, probably not’ or ‘No, definitely, not’.



Section 6 | Diagnosis

This chapter sets out to understand the current attitudes and barriers to dementia diagnosis, as well as people’s attitudes to potential future developments in diagnosis and technology.

6.1 | BEING GIVEN A FORMAL DIAGNOSIS OF DEMENTIA

There is widespread support for people with dementia being given a formal diagnosis from a doctor: 82% agree that there is value in doing so, compared with just three per cent who disagree.



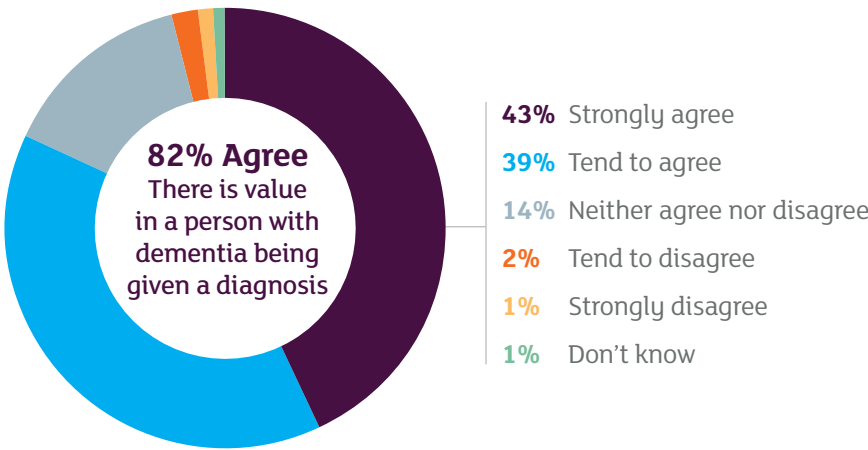
Differences by characteristics in attitudes to being given a diagnosis include:

- Those aged 45-54 years are more likely to agree (89%) that there is value in a person with dementia being given a formal diagnosis, than people who are younger (81% of those aged 44 and under) and older (79% of those aged 55 years and above).
- People in the youngest age group (15 to 24 years) are the least confident in terms of knowing whether there is value in being given a formal diagnosis (19% say ‘neither agree nor disagree’, compared with 14% overall). This correlates with the finding that people from black, Asian and minority ethnic backgrounds, who have a younger age profile, are also less sure (20% say ‘neither agree nor disagree’, compared with 13% of participants who are white).

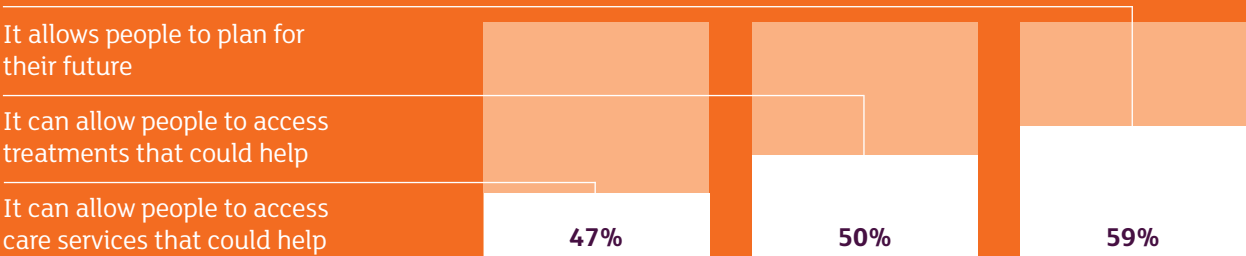
The survey included follow-up questions designed to understand the reasons behind individuals’ attitudes towards the value of a formal diagnosis. The most commonly selected reason as to why there is a value in a formal diagnosis from a doctor is to ‘... allow people to plan for their future’ (59%). Half (50%) feel that a diagnosis can allow people to access treatments that could help and a further 47% feel that a diagnosis allows people to access care services that could help. Responses are shown in the chart opposite.

Overall, just three per cent of people disagree that there is value in a person being given a formal diagnosis from a doctor²⁴. The most common reasons given are that it is too stressful for the individual involved (43%), and there are no treatments available that can make a difference (21%).

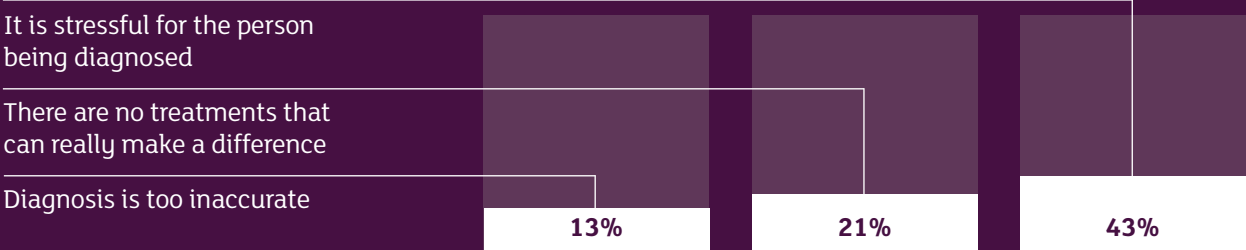
Do you agree or disagree with the following statement ‘There is value in a person with dementia being given a formal diagnosis from a doctor’?



Reasons why people agree (%)



Reasons why people disagree (%)*



Base: Adults 15+ in UK (2,361) Base: Adults who agree (1,906) Base: Adults who disagree (77)
* Top reasons why people disagree. Note small base size of less than 100. Findings should be treated as indicative only.

6.2 | UNDERGOING TESTS FOR DEMENTIA

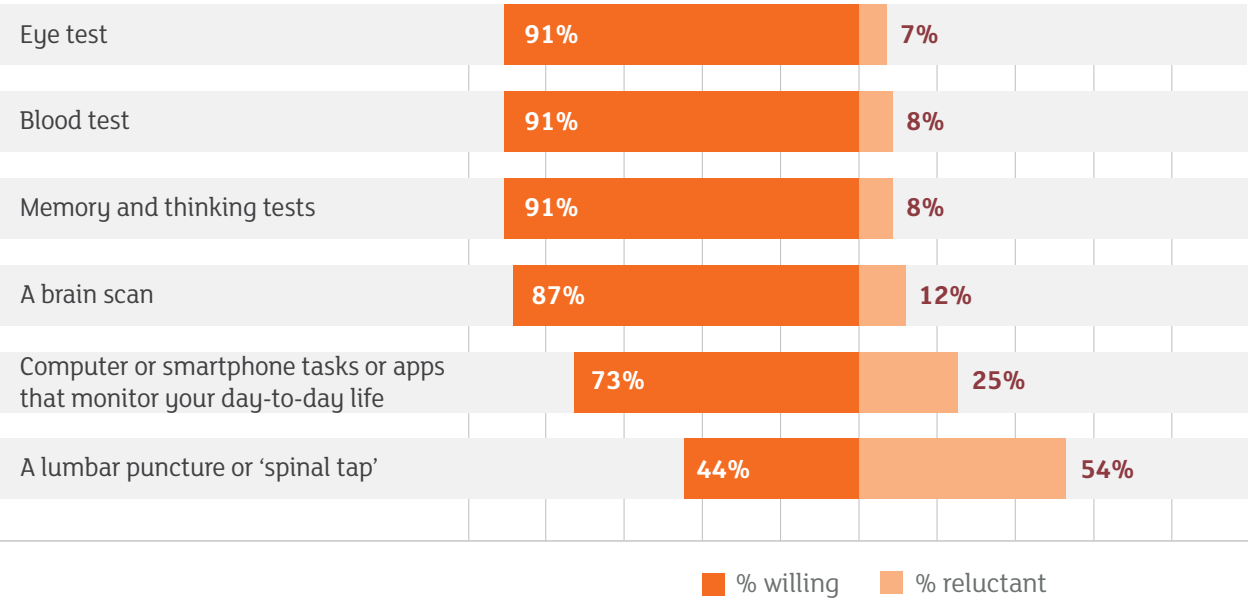
Moving from the general to the personal, people were asked how willing, or reluctant, they would be to take a particular clinical test to aid a doctor in making an accurate and early diagnosis, if they were concerned that they might be in the early stages of Alzheimer’s or another form of dementia²⁵.

Current UK NICE guidelines²⁶ for dementia recommend a combination of memory and thinking tests, with brain scans including MRI scans providing further clarification. Recent updates to the guidance in 2018 now include lumbar puncture or ‘spinal taps’ as a way of assisting the diagnosis of Alzheimer’s disease in cases that are particularly complex or unclear. The research community is particularly active in driving new developments in diagnostics, including eye scans, blood tests and the use of technology to track aspects of health such as sleep, gait, and verbal fluency.

As shown in the chart below, the vast majority of people would be willing to undergo less invasive tests such as an eye test, a blood test and a memory/thinking test (all mentioned by 91%). Most people would also agree to a brain scan (87%). Three-quarters of people are open to new technology to make an accurate and early diagnosis and would agree to using computer/smartphone tasks that monitor day-to-day life (73%).

More people are reluctant to undergo a lumbar puncture/spinal tap to make an accurate and early diagnosis in the initial stages of dementia than are willing to do so (54%, compared with 44%). Although, given the invasive nature of the procedure it is interesting to note that over two in five people say they would be willing to go ahead with such a test.

How willing or reluctant would you be for doctors to use one of the following tests to make an accurate and early diagnosis?



Base: Adults aged 15+ in the UK without a dementia diagnosis (2,354)

Reluctance to undergo approaches that are currently available, or are being developed, to diagnose dementia is more common amongst the following groups:

- *Older people:* those aged 55 or over are more reluctant to undergo memory tests, a brain scan or eye tests, or complete tests via a computer/smartphone, than younger people.
- *Those who are not working:* reluctance to take memory tests, brain scans, eye tests and computer/smartphone tasks that monitor day-to-day life is higher among those who are not working, compared to those who are.
- *People with no formal qualifications:* this group is less inclined to take memory tests, brain scans, eye tests, and computer/smartphone tasks that monitor day-to-day life, than those who hold qualifications.
- For all tests, those who do not want to know about their own personal risk of developing dementia later in life, people who do not see value in someone with dementia being given a formal diagnosis by a doctor and those who do not think current dementia treatments are effective, are more reluctant to undergo tests that would help to make an early diagnosis.

Looking ahead to the development of apps or computer-based programmes, as highlighted above, future generations are likely to be much more open to innovative health techniques than today’s older people (82% of those aged 15-44 years say they are willing to use computer or smartphone tasks or apps that monitor your day to day life, compared with 51% of those aged 65 years or over).

Attitudes towards undergoing a lumbar puncture are less diverse. However, a significantly higher proportion of men (47%) are willing to go through the procedure, compared with women (40%). It is interesting to compare these results with the European Attitudes to Alzheimer’s Disease survey. Overall the findings are comparable with 46% willing to take a spinal tap²⁷ and lower willingness among women to undergo the test, than men.

6.3 | ATTITUDES TO BEING TESTED FOR DISEASES THAT CAUSE DEMENTIA

As efforts to develop life-changing treatments for dementia are evolving, it’s becoming clear that treating people as early as possible in the disease process is likely to yield the greatest benefit for those affected. To allow future treatments to have the biggest impact, researchers predict that there will be a need to start

detecting diseases like Alzheimer’s 10-15 years before symptoms start to show.

This would involve a significant shift in clinical practice, as well as a shift in mindset of the public with greater awareness of brain health as well as a willingness to engage with diagnosis, research and treatment at a stage where someone was not experiencing noticeable changes to their cognitive health. Attitudes towards this shift in diagnosis is explored in the Dementia Attitudes Monitor.

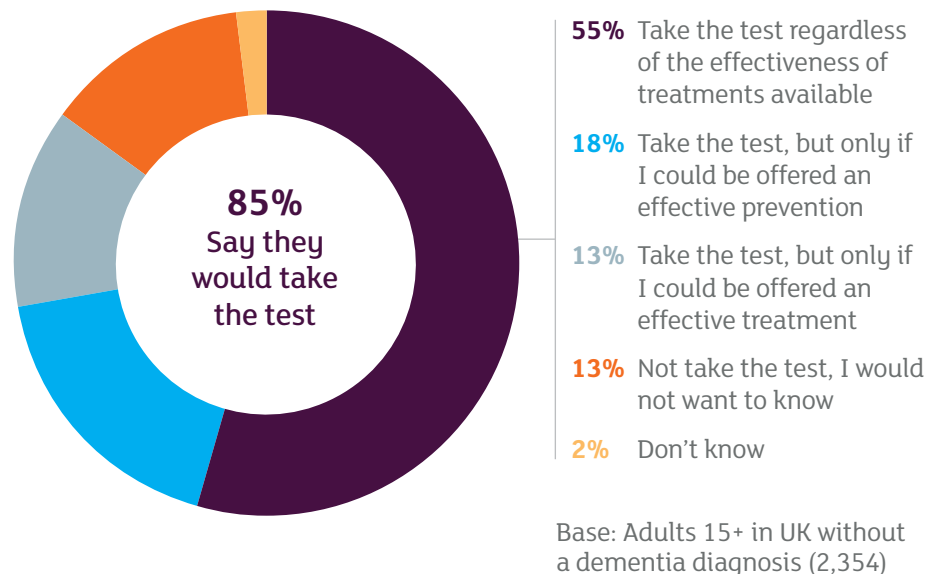
The vast majority of people (85%) say they would take a test, or set of tests, through their doctor, that could tell whether they were in the very early stages of Alzheimer’s or another form of dementia, even before the symptoms showed. However, there are caveats to this, with one in six people (18%) indicating that they would only take the test if they could be offered an effective prevention and one in eight (13%) only doing so if they could be offered effective treatment. However, just over half (55%) would still take the test regardless of the effectiveness of treatments available²⁸.



Section 7 | Treatment, prevention & research

This chapter highlights people's awareness and understanding of current dementia treatments and their priorities for medical research into Alzheimer's disease and other forms of dementia in the future.

Imagine that you were able to take a test through your doctor that could tell you whether you were in the very early stages of Alzheimer's or another form of dementia, would you?



As shown in the chart above, overall, 13% of people say they would not take the test because they would not want to know if they were in the very early stages of Alzheimer's or another form of dementia.

Knowing someone with dementia can affect people's attitudes towards potentially taking a test, or set of tests, that would tell whether they were in the very early stages of Alzheimer's or another form of dementia. Three in five people with experience of dementia (59%) would take the test, regardless of effective treatments being available, compared with half (50%) of those with no experience.

Variations between subgroups are like those highlighted in response to questions about specific tests:

- *Older people*: those aged 55-64 years (17%) and 65 and over (16%) are more likely to say that they would not take the test, compared to people aged between 25-34 years (10%) and 35-44 years (nine per cent);
- *People with no formal qualifications* are more likely to say they would not take the test, than those who hold qualifications at A level, degree or higher levels (20%, compared with 11%).

- Once again, there is consistency in attitudes, with people who do not think they would take a test more likely to be those who do not want to know about their own personal risk of developing dementia later in life (34%), people who do not see value in someone with dementia being given a formal diagnosis by a doctor (33%) and those who do not think current dementia treatments are effective (15%).

Overall the findings show a strong public appetite for the early detection and diagnosis of the diseases that cause dementia. While there are several barriers that need overcoming to enable the NHS to move towards pre-symptomatic detection of diseases like Alzheimer's²⁹, these data show that public willingness for such a move is unlikely to be a major barrier to overcome. However, it does highlight those groups less likely to engage with new developments, including those over 55. The over 55s are a key demographic for the early diagnosis of the diseases that cause dementia, showing that work must continue to communicate the potential benefits and opportunities presented by any new developments in diagnosis, as well as ensuring people understand the implications of receiving such information.

7.1 | EFFICACY OF CURRENT DEMENTIA TREATMENTS

While there are currently no drug treatments that prevent, slow or stop the underlying diseases that cause dementia, treatments have been developed to help people manage their symptoms day-to-day. While current NICE guidelines for dementia recommend a range of possible non-drug treatments such as cognitive stimulation, the specific dementia medicines that are available are only approved for those with Alzheimer's disease and dementia with Lewy bodies. Some people taking these medicines may notice an improvement whereas others may notice their condition stays the

same when they would have expected it to worsen. Others may feel no benefit.

The Dementia Attitudes Monitor set out to explore the public's understanding by asking how effective they think current dementia treatments are. Overall, 50% of people say that current dementia treatments are not effective; just a quarter (27%) consider them to be effective. One in five people (22%) are unsure either way.

The table on the next page highlights how attitudes towards the efficacy of current dementia treatments vary by age, education, social grade and experience of knowing someone with the condition.

How effective or not do you think current dementia treatments are?

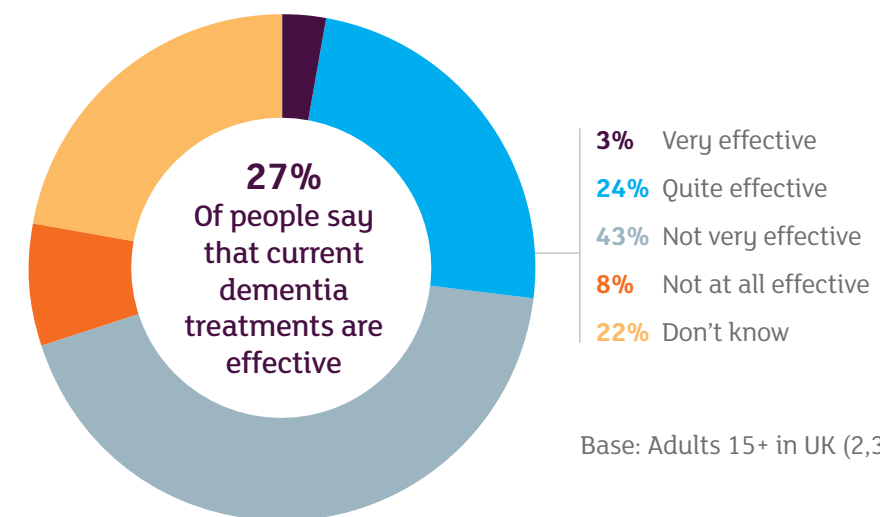


Table 7.1: Attitudes towards the effectiveness of dementia treatments

How effective or not do you think current dementia treatments are?			
	Base	Effective	Not effective
TOTAL	2,361	27%	50%
AGE			
15-24 year olds	341	34%	40%
65+ year olds	594	24%	54%
EDUCATION			
Degree/Masters/ Phd level or equiv.	703	21%	59%
No formal qualifications	328	28%	49%
SOCIAL GRADE			
AB	518	23%	57%
C1	777	27%	50%
C2	501	31%	47%
DE	565	29%	47%
EXPERIENCE OF DEMENTIA			
Any experience	1,163	25%	59%
No experience	1,174	29%	41%

7.2 | AWARENESS OF DEMENTIA TREATMENTS

When asked to indicate which, if any, of eight possible treatments they believe currently exist as ways to treat dementia, people are most likely to pick those that help to support people living with the condition such as group therapy activities to stimulate memory, thinking and language skills (44%), activity sessions to help improve mood and wellbeing through music, games and photographs (41%) and support to develop techniques that help people with day-to-day activities (40%).

Approaching three in five people (56%) suggest that medicines are available to treat dementia, most frequently mentioning ‘*medicines on NHS prescription that can help relieve symptoms*’ (36%).

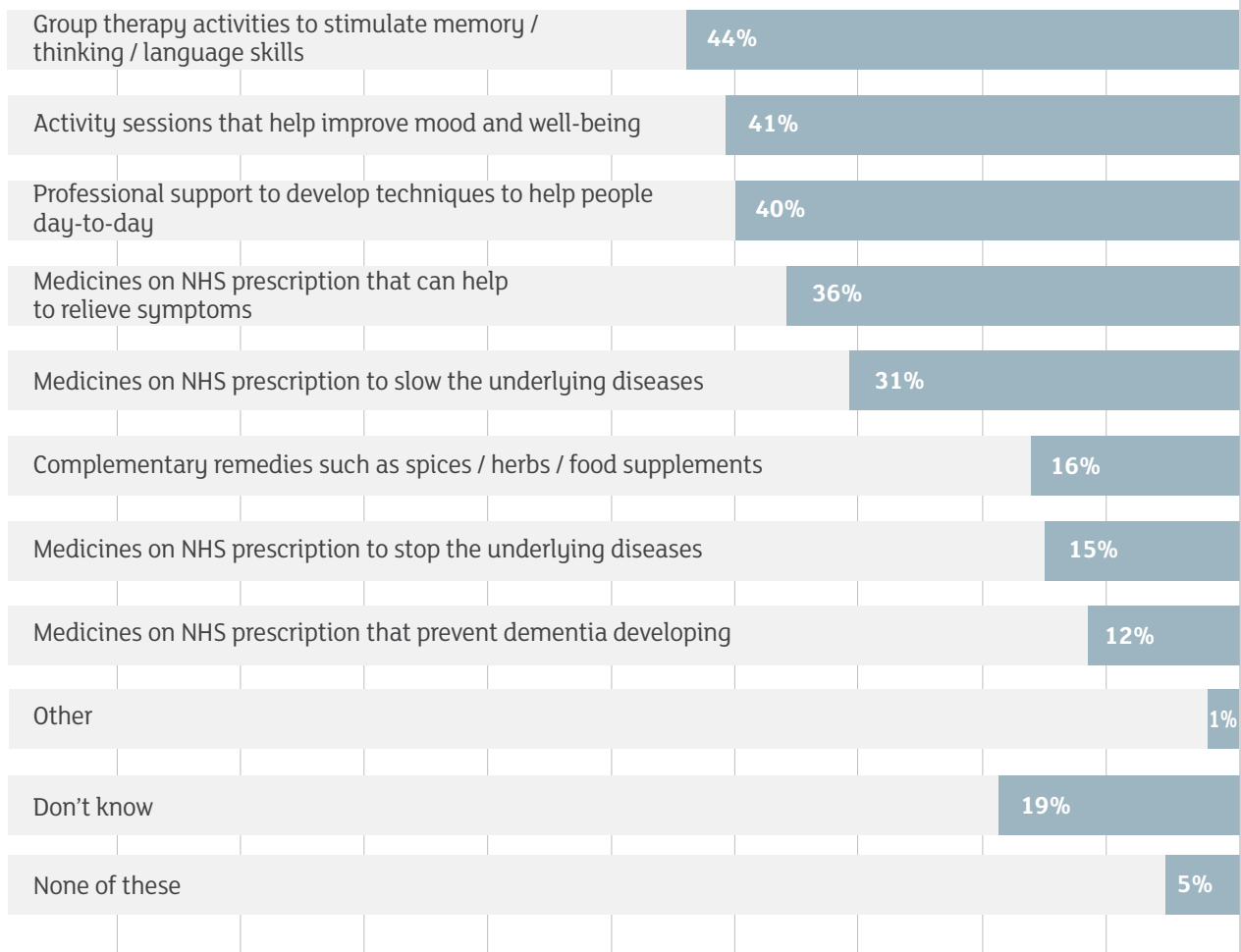
However, despite the absence of treatment to slow, stop or prevent the diseases like Alzheimer’s that cause dementia, 31% suggest that there are ‘*medicines on NHS prescription to slow down the underlying diseases that cause dementia*’, over one in ten mention

‘*medicines on NHS prescription to stop the underlying diseases that cause dementia*’ (15%) and just over one in ten (12%) people select the statement ‘*medicines on NHS prescription that prevent dementia developing in the first place*’.

This highlights a lack of clarity from the public about what treatments for dementia are available. This may be influencing their perception of how effective current dementia treatments are, which in turn may influence how likely they are to engage with campaigns relating to early diagnosis, risk reduction or research involvement.

Those who say ‘don’t know’ when asked what currently exists in terms of treating dementia are more likely to be from a black, Asian and minority ethnic background (29%, compared with 18% of those from a white background), those with no formal qualifications (29%, compared with 14% of people educated to degree level) and those with no contact with someone living with dementia (25%, compared with 15% of people with any experience of dementia).

Which, if any, of the following currently exists as a way to treat dementia?



Base: Adults aged 15+ in the UK (2,361)

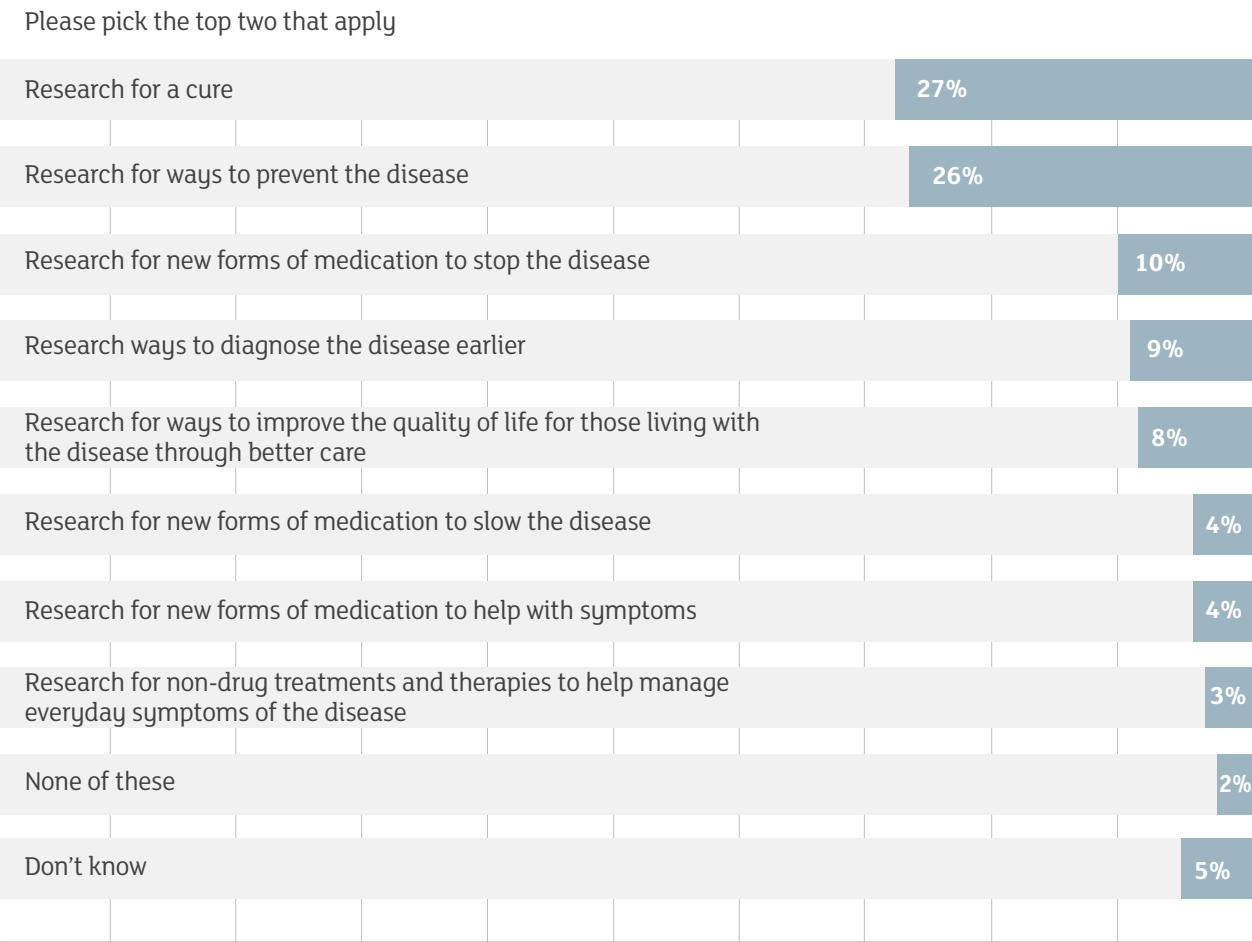
7.3 | PRIORITIES FOR MEDICAL RESEARCH

The Dementia Attitudes Monitor asked people to consider which type of medical research into Alzheimer’s disease or other forms of dementia is the most important from a list of eight. The most important priorities for medical research are ‘Research for a cure’ (27%), closely followed by ‘Research for ways to prevent the disease’ (26%). When asked to select the second most important form of research the same two issues are highlighted.

Some groups emphasise prevention over finding a cure, including:

- *People with experience of dementia*: around three in ten people who have friends, family or someone else close to them who has experienced dementia prioritise the need for prevention over a cure (30% and 27%, respectively).
- *Those educated to degree level*: a third of the people in this group highlight the importance of research into prevention, compared with research into a cure (33% and 24%, respectively).

Which, if any, of the following types of medical research into Alzheimer’s disease or other forms of dementia would you say are most important?



Base: Adults aged 15+ in the UK (2,361)

• *Middle to higher income groups:* for people earning £25,000-£29,999 and more than £30,000 the most important type of medical research relates to preventing, rather than curing, dementia (28% and 26%, respectively).

7.4 | INVOLVEMENT IN MEDICAL RESEARCH FOR DEMENTIA

To bring about effective new preventions and treatments for dementia, Alzheimer’s Research UK is keen to encourage more people to get involved in dementia research. Initiatives like Join Dementia Research³⁰, launched in 2015, have already seen over 38,000

people register their interest in volunteering for research.

Half of the people who participated in the Dementia Attitudes Monitor would, hypothetically, be willing to get involved in medical research for dementia in the future; 20% would not and a further 28% are unsure.

By age, people over the age of 65 are least likely to consider getting involved in medical research for dementia (31%, compared with 20% overall). Similar variations were found by education level, with 31% of people with no formal qualifications saying ‘No, I wouldn’t’, compared with 12% of people educated to degree level.

People from a white ethnic background are more likely to consider getting involved in medical research for dementia than those from black, Asian and minority ethnic backgrounds (51% compared to 44%).

Those with children at home are more willing to get involved (57%) compared to those without children (48%), as are those with personal experience of dementia (56%) compared to those with no experience of the condition (44%).

Although not directly comparable in methodology, the findings in this Monitor are lower than those reported in previous surveys, with an Alzheimer’s Research UK poll in 2013 showing that 57% of UK adults would consider getting involved in dementia research.

In order to better understand the public’s willingness to engage in medical research for dementia, Alzheimer’s Research UK included the same question in a regular Ipsos MORI poll of 2,011 nationally representative adults aged 15+ in the UK conducted in October 2018. In addition to asking whether or not people would be willing to get involved in medical research for dementia in the future, participants were asked to provide reasons for their answer.

This time, when the question was not asked within the wider context of the Dementia Attitudes Monitor, just 39% said they would be willing to get involved in medical

research for dementia; 38% would not and a further 21% were unsure. This highlights the importance of how such a question is presented and framed, and the effect that such framing can have on someone’s consideration to participate in research.

Of those aged 55 and above, perhaps the most important age group for research involvement, who would be willing to get involved in medical research for dementia, the main reason given was ‘Research is the only answer to dementia and I would want to play my part’, followed by ‘I have a family member or friend affected by dementia and I would want to play my part’. The main reason given by those aged 55 and above who would not be willing to get involved in research is that ‘I don’t know enough about what it would involve’, followed by ‘I don’t have enough time’.

Better understanding the reasons why there may be a reluctance to get involved in medical research into dementia is vital for developing campaigns to overcome these barriers, and ensure research efforts have enough willing volunteers to deliver advances in research.

This Dementia Attitudes Monitor now acts as a benchmark to track the impact of future campaigns to encourage research involvement, including those led by the National Institute for Health Research, and charities such as Alzheimer’s Research UK.



Section 8 | Appendices: Technical details

8.1 | METHODOLOGY

Sampling and fieldwork

Ipsos MORI carried out 2,361 interviews among a representative sample of adults aged 15 years and over living in the UK.

The questions were placed on the Ipsos MORI Capibus survey, a weekly face-to-face omnibus survey of a representative sample of people aged 15 and over in the UK.

The face-to-face omnibus uses a rigorous sampling method - a form of random location sampling, using a control method applied to field region and subregion over a robust number of sample points (typically 170-180) to ensure a good geographical spread. Interviewers are then sent quotas for gender, age, working status and tenure to ensure our sample is nationally representative. CACI ACORN geo-demographic system is used in the selection process.

The interviewer is required to achieve interviews with respondents from a small set of homogenous streets, selected with probability proportional to population after stratification by ACORN characteristics and region.

All interviews were conducted face-to-face and in-home, between 15 June and 5 July 2018. Interviews were conducted using CAPI (computer-assisted personal interviewing).

8.2 | REFERENCED REPORTS

Where relevant, this report draws on research and data from other publications, produced both by Ipsos MORI and other organisations. Where other data is used, this is clearly referenced in a footnote. Below is a summary of these publications:

- 2017 Health, Ageing and Support Survey, Ipsos MORI research for the Department of Health and Social Care, to be published in 2018, available on the Gov.uk website
- 2016 Public Perceptions of the NHS Tracker Survey, Ipsos MORI research for the Department of Health and Social Care, to be published in 2018, available on the Gov.uk website

- NatCen Social Research 2015 British Social Attitudes Survey, NatCen research for Public Health England.
- 2018 European Attitudes to Alzheimer’s: Disease, diagnosis, diagnostics and interventions, Censuswide research for MSD

8.3 | GUIDE TO STATISTICAL RELIABILITY

How accurately does the survey reflect the views of the UK population? It should be remembered that a sample of the UK population aged over 15, not the whole population, has been interviewed. In consequence, all results are subject to sampling tolerances, which means that not all differences between results are statistically significant, at the 95% confidence level. For example, for a question where 50% of the people in a weighted sample of 2,361 respond with a particular answer, the chances are 95 in 100 that this result would not vary more than plus or minus two percentage points from the result that would have been obtained from a census of the entire population (using the same procedures).

Indications of approximate sampling tolerances for this survey, and for surveys of smaller groups of participants, are provided in the table opposite. As shown, sampling tolerances vary with the size of the sample and the size of the percentage results. This survey used a quota sampling approach. Strictly speaking the tolerances applied here apply only to random samples with an equivalent design effect. In practice, good quality quota sampling has been found to be almost as accurate³¹.

Approximate sampling tolerances applicable to percentages at or near these levels at the 95% confidence level			
	10% or 90%	30% or 70%	50%
Size of sample on which survey result is based	±	±	±
220 interviews	4	6	7
500 interviews	3	4	4
750 interviews	2	3	4
1000 interviews	2	3	3
2,361 interviews	1	2	2

Comparing the views of different groups within the sample surveyed

Different groups within a sample (e.g. men and women) may have different results for the same question. A difference has to be of a certain size in order to be statistically significant. To test if a difference in results between two subgroups within a sample is statistically significant, at the 95% confidence level, the differences between the two results must be greater than the values provided in the table below. Again, strictly speaking the sampling tolerances shown here apply only to random samples with an equivalent design effect. In practice, good quality quota sampling has been found to be almost as accurate³².

Differences required for significance at or near these percentages at the 95% confidence level			
	10% or 90%	30% or 70%	50%
Size of sample on which survey result is based	±	±	±
100 and 100	8	13	14
200 and 200	7	10	11
300 and 300	5	7	8

Only subgroups comprising 100 or more participants are commented on in this report, unless an exception is noted. It should be noted, however, that the smaller the size of the subgroup, the less we can rely on the survey estimates to be true representatives of the population as a whole. Findings for groups with as few as 100 participants can be subject to confidence intervals of +/-10%.

In addition to being statistically significant, only subgroup differences which are interesting and relevant to the question being analysed are commented on in the report.

8.4 | GUIDE TO SOCIAL CLASSIFICATION

In this report, references are made to social grade. The following table contains a brief list of social grade definitions as used by the Institute of Practitioners in Advertising. These groups are standard on all surveys carried out by Ipsos MORI.

Social Grade	Social Class	Occupation of Chief Income Earner
A	Upper Middle Class	Higher managerial, administrative or professional
B	Middle Class	Intermediate managerial, administrative or professional
C1	Lower Middle Class	Supervisor or clerical and junior managerial, administrative or professional
C2	Skilled Working Class	Skilled manual workers
D	Working Class	Semi and unskilled manual workers
E	Those at the lowest levels of subsistence	State pensioners, etc, with no other earnings

8.5 | TOPLINE

The following questionnaire was developed by Ipsos MORI in close liaison with Alzheimer’s Research UK. Below, we have included the topline results to each question.

- Results are based on 2,361 interviews conducted among a representative sample of adults aged 15+, living in the UK. Interviews were conducted face-to-face in participants’ homes between 15 June – 5 July 2018.
- Where results do not sum to 100%, this may be due to multiple responses, computer rounding or the exclusion of ‘don’t know/ not stated’ response categories. Please note that questionnaire changes occur between waves and therefore certain questions are not asked across each wave.
- An asterisk (*) represents a value of less than half of one per cent, but not zero.
- Results are based on all 2,361 interviews unless otherwise stated.

ASK ALL

Q1 Which, if any, of the following health conditions do you think it’s possible for people to reduce their risk of developing? MULTI CODE.

	%
Diabetes	81
Heart disease	77
Stroke	60
Cancer	52
Dementia	34
None of these	3
Don’t know	2

Base: 2,361 (Adults aged 15+ in the UK)

ASK ALL

Q2 What words come to mind when I say dementia?

	%
Memory loss / forgetfulness	52
Old age / elderly	20
Emotional response	18
Confusion	13
General descriptors	10
Personal connection	6
Physical descriptors	6

Base: 1,168 (Adults aged 15+ in the UK – Half sample 1). Responses from more than 5% of the sample shown above. Full list can be found in the tables.

ASK ALL ON VERSION 1

Q2A In a few words, can you describe what happens to a person’s brain when they get dementia to cause symptoms such as memory loss? [UNPROMPTED LIST]

	%
Brain cells dying	32
Brain stops working properly/slows down	32
Degeneration	32
Damage to brain cells	27
Disease	12
Don’t know	15

Base: 1,168 (Adults aged 15+ in the UK – Half sample 1). Responses from more than 5% of the sample shown above. Full list can be found in the tables.

ASK ALL ON VERSION 2

Q3 What words come to mind when I say Alzheimer’s disease?

	%
Memory loss / forgetfulness	52
General symptoms	18
Old age / elderly	16
Confusion	16
General descriptors	15
Emotional response	15
Personal connection	6
Physical descriptors	5

Base: 1,193 (Adults aged 15+ in the UK – Half sample 2). Responses from more than 5% of the sample shown above. Full list can be found in the tables.

ASK ALL ON VERSION 2

Q3B In a few words, can you describe what happens to a person’s brain when they get Alzheimer’s disease to cause symptoms such as memory loss? [UNPROMPTED LIST]

	%
Degeneration	36
Brain cells dying	31
Brain stops working properly/slows down	31
Damage to brain cells	27
Disease	12
Don’t know	13

Base: 1,193 (Adults aged 15+ in the UK – Half sample 2). Responses from more than 5% of the sample shown above. Full list can be found in the tables.



ASK ALL

Q4 [INSERT COMMENT FOR VERSION 2 ONLY] “Alzheimer’s disease is the most common form of dementia”. Has a close friend, a member of your family or someone else you know been diagnosed as having a form of dementia such as Alzheimer’s disease?

PROBE FULLY Who else? MULTI CODE. ALLOW REF.

	%
Yes, myself	*
Yes, close friend(s)	5
Yes, other friend(s)	5
Yes, partner or spouse	1
Yes, parent(s), step-parent(s)	11
Yes, grandparent(s)	15
Yes, brother(s), sister(s), stepbrother(s), stepsisters(s)	1
Yes, other close family member(s)	8
Yes, other family member(s)	7
Yes, work colleagues(s)/former colleague(s)	1
Yes, neighbour(s)/someone else from local community	4
Yes, a person other than those listed above	6
No, no-one close to me has been diagnosed	43
Don’t know	5
Prefer not to say	1

ASK ALL

Q5 I am now going to read out a number of statements. For each one please tell me the extent to which you agree or disagree? SINGLE CODE AND ALLOW DK.

1. Dementia affects physical aspects of a person’s health

	%
Strongly agree	27
Tend to agree	47
Neither agree nor disagree	13
Tend to disagree	9
Strongly disagree	3

2. Dementia affects mental aspects of a person’s health

	%
Strongly agree	66
Tend to agree	27
Neither agree nor disagree	5
Tend to disagree	1
Strongly disagree	1

3. Dementia is an inevitable part of getting older

	%
Strongly agree	4
Tend to agree	18
Neither agree nor disagree	17
Tend to disagree	33
Strongly disagree	27

4. Dementia is a cause of death

	%
Strongly agree	18
Tend to agree	33
Neither agree nor disagree	22
Tend to disagree	18
Strongly disagree	7

Base: 2,354 (Adults aged 15+ in the UK – without a dementia diagnosis).

5. Dementia is the health condition I fear most about getting in the future

	%
Strongly agree	17
Tend to agree	25
Neither agree nor disagree	21
Tend to disagree	24
Strongly disagree	12

Base: 2,354 (Adults aged 15+ in the UK – without a dementia diagnosis).

6. If I was diagnosed with dementia, I would feel comfortable telling people outside my close family

	%
Strongly agree	23
Tend to agree	36
Neither agree nor disagree	17
Tend to disagree	16
Strongly disagree	7

Base: 2,354 (Adults aged 15+ in the UK – without a dementia diagnosis).

7. I would find it hard to talk to someone who has dementia

	%
Strongly agree	5
Tend to agree	16
Neither agree nor disagree	15
Tend to disagree	31
Strongly disagree	30

Base: 2,354 (Adults aged 15+ in the UK – without a dementia diagnosis).

ASK ALL

Q6 What, if anything, do you think could increase a person’s risk of developing dementia?

DO NOT PROMPT. PROBE FULLY What else?

MULTI CODE – DO NOT READ OUT.

	%
Being less mentally active	34
Being overweight	5
Depression	15
Diabetes	4
Drinks containing caffeine	2
Fewer years in education	2
Genetic factors e.g. having a parent with dementia	25
Hearing loss	2
Heart disease	3
Heavy drinking	16
High blood pressure	5
High cholesterol	3
Lack of exercise	17
Old age	23
Poor diet	16
Previous head injury	10
Smoking	11
Using aluminium pots and pans	2
Loneliness	18
Stress	10
Other – Please specify	3

ASK ALL

Q7. And which, if any, of the following do you think could increase a person’s risk of developing dementia? PROBE FULLY What else?

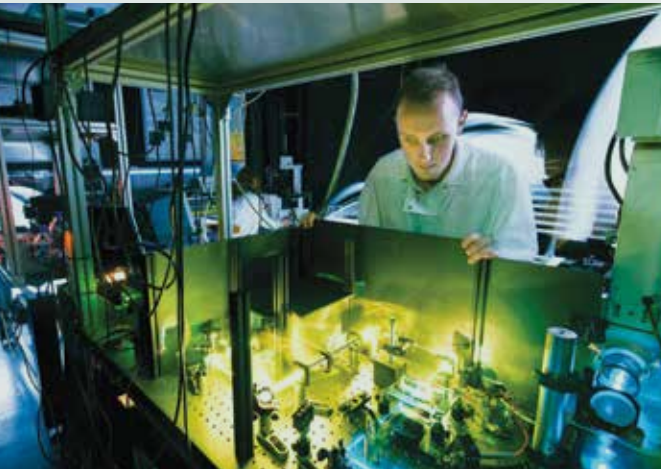
MULTI CODE. RANDOMISE STATEMENTS.

	%
Being less mentally active	24
Being overweight	10
Depression	23
Diabetes	7
Drinks containing caffeine	3
Fewer years in education	3
Genetic factors e.g. having a parent with dementia	26
Hearing loss	3
Heart disease	6
Heavy drinking	16
High blood pressure	10
High cholesterol	8
Lack of exercise	13
Old age	33
Poor diet	12
Previous head injury	20
Smoking	12
Using aluminium pots and pans	4
Loneliness	20
Stress	21

ASK ALL

Q8 If doctors were able to give you information in midlife about your personal risk of developing dementia in later life, based on your genetics and/or lifestyle, would you want/have wanted to know or not? SINGLE CODE. ALLOW DK.

	%
Yes, definitely	47
Yes, probably	26
No, probably not	15
No, definitely not	11



ASK ALL

Q9 Please answer the following question based on your understanding of the current diagnosis, treatment and care options for people with dementia.

Do you agree or disagree with the following statement....?
“There is value in a person with dementia being given a formal diagnosis from a doctor”
SINGLE CODE. ALLOW DK.

	%
Strongly agree	43
Tend to agree	39
Neither agree nor disagree	14
Tend to disagree	2
Strongly disagree	1

ASK ALL WHO AGREE THAT THERE IS VALUE IN A PERSON WITH DEMENTIA BEING GIVEN A FORMAL DIAGNOSIS FROM A DOCTOR (Q9 = 1 or 2)

Q10 You said that you agree that there is value in a person with dementia being given a formal diagnosis from a doctor. Why do you say that? **PROBE FULLY:** For what other reasons?
MULTI CODE – RANDOMISE CODES 1-6. ALLOW NULL AND DK.

	%
It can allow people to access treatments that could help	50
It can allow people to access care services that could help	47
It allows people to plan for their future	59
It could allow access to financial support or benefits	29
It could provide opportunities for people to get involved in research/trials	30
It could provide peace of mind to those worrying about the cause of their symptoms	2
Other – please specify	3

Base: 1,906 (Adults aged 15+ in the UK who agree at Q9).

ASK ALL WHO DISAGREE THAT THERE IS VALUE IN A PERSON WITH DEMENTIA BEING GIVEN A FORMAL DIAGNOSIS FROM A DOCTOR (Q9 = 4 or 5)

Q11. You said that you disagree that there is value in a person with dementia being given a formal diagnosis from a doctor. Why do you say that?
PROBE FULLY: For what other reasons?
MULTI CODE – RANDOMISE CODES 1-6. ALLOW NULL AND DK.

The stigma of a diagnosis is too great	5
There are no treatments that can really make a difference	21
It’s just part of getting older	10
It is stressful for the person being diagnosed	43
Diagnosis is too often inaccurate	13
It could cause practical problems like stopping driving or trouble getting insurance	10
Other – please specify	7

Base: 77 (Adults aged 15+ in the UK who disagree at Q9).



ASK ALL WHO ARE WITHOUT A DIAGNOSIS

Q12. There are many approaches being developed that could improve how a diagnosis of dementia is made in the future. If you were concerned that you might be in the early stages of Alzheimer’s or another form of dementia, how willing or reluctant would you be for doctors to use one of the following tests to make an accurate and early diagnosis?
SINGLE CODE AND ALLOW DK PER STATEMENT – RANDOMISE THE ORDER OF THE STATEMENTS.

	Memory and thinking tests	A brain scan	A lumbar puncture or ‘spinal tap’ where a spinal fluid sample is taken using a needle in the base of the spine	Blood test	Eye test	Computer or smartphone tasks or apps that monitor your day-to-day life
Very willing	67%	60%	20%	67%	69%	46%
Fairly willing	24%	28%	24%	24%	23%	27%
Fairly reluctant	5%	7%	25%	5%	4%	13%
Very reluctant	3%	4%	29%	3%	3%	12%
Don’t know	1%	1%	2%	1%	1%	2%

Base: 2,354 (Adults aged 15+ in the UK – without a dementia diagnosis).

ASK ALL WHO ARE WITHOUT A DIAGNOSIS

Q13. Imagine you were able to take a test, or set of tests, through your doctor that could tell you whether you were in the very early stages of Alzheimer’s or another form of dementia, even before symptoms showed, would you...?
SINGLE CODE. ALLOW DK AND REF.

	%
Take the test regardless of the effectiveness of treatments available	55
Take the test, but only if I could be offered an effective prevention	18
Take the test, but only if I could be offered an effective treatment	13
Not take the test.	13

Base: 2,354 (Adults aged 15+ in the UK – without a dementia diagnosis).

ASK ALL

Q14. How effective or not do you think current dementia treatments are?
SINGLE CODE. ALLOW DK.

	%
Very effective	3
Quite effective	24
Not very effective	43
Not at all effective	8

ASK ALL

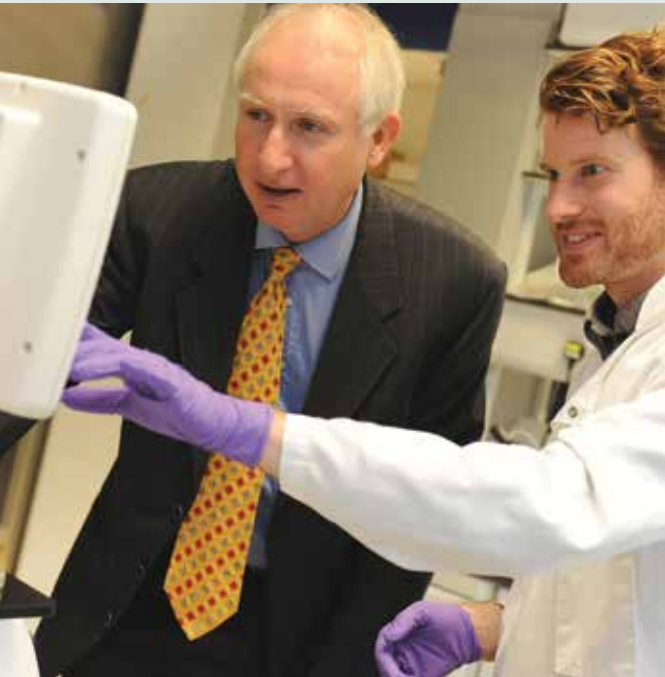
Q15. Which, if any, of the following currently exist as ways to treat dementia?

PROBE FULLY Which others?

MULTI CODE – ROTATE THE ORDER OF THE STATEMENTS

1-8. ALLOW NULL AND DK.

	%
Medicines on NHS prescription that can help to relieve symptoms	36
Medicines on NHS prescrp. to slow the underlying diseases that cause dementia	31
Medicines on NHS prescription to stop the underlying diseases that cause dementia	15
Medicines on NHS prescription that prevent dementia developing in the first place.	12
Group therapy activities to stimulate memory, thinking and language skills (cognitive stimulation)	44
Professional support to develop techniques that help people with day-to-day activities (cognitive rehabilitation)	40
Activity sessions that help improve mood and wellbeing through music, games and photographs	41
Complementary remedies such as spices, herbs or food supplements	16
Other – please specify	1



ASK ALL

Q16. Which, if any, of the following types of medical research into Alzheimer’s disease or other forms of dementia would you say are most important? Please pick the top two that apply

ROTATE THE ORDER OF THE STATEMENTS 1-8. ALLOW NULL AND DK.

	%
Research for a cure	27
Research for new forms of medication to slow the disease	4
Research for new forms of medication to stop the disease	10
Research for new forms of medication to help with symptoms	4
Research for non-drug treatments and therapies to help manage everyday symptoms of the disease	3
Research for ways to diagnose the disease earlier	9
Research for ways to prevent the disease	26
Research for ways to improve the quality of life for those living with the disease through better care	8
Other – please specify	-

ASK ALL

Q17. The next question is purely to gauge whether the general public would consider involvement in the future. You will NOT be asked to take part in any type of medical research – it is purely your opinion we are interested in.

Regardless of any memory issues you might have... hypothetically, would you consider getting involved in medical research for dementia in the future?

[SINGLE CODE]

	%
Yes, I would	50
No, I wouldn’t	20
Not sure	28
Rather not say	2

Section 9 | References

¹ www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health

² www.dementiastatistics.org/statistics/prevalence-projections-in-the-uk

³ www.dementiastatistics.org/statistics/cost-and-projections-in-the-uk-and-globally

⁴ www.dementiastatistics.org/statistics/deaths-due-to-dementia

⁵ 2016 Public Perceptions of the NHS Tracker Survey, Ipsos MORI research for the Department of Health and Social Care.

⁶ 2017 Health, Ageing and Support Survey, Ipsos MORI research for the Department of Health and Social Care.

⁷ YouGov polling for Alzheimer’s Research UK 25 – 26 June 2018. Total sample size was 2,096 adults. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+).

⁸ Social grades A, B and C1 are the middle class socio-economic grades, whereas grades C2, D and E are the working class socio-economic grades. Please refer to Section 8.4 in the appendices for a fuller definition of social grades.

⁹ NatCen Social Research – British Social Attitudes (Attitudes to Dementia), 2015.

¹⁰ The unprompted verbatim answers were grouped together for analysis purposes.

¹¹ The unprompted verbatim answers were grouped together for analysis purposes.

¹² The study showed that less than 20% of participants in any country thought that Alzheimer’s disease was a normal part of ageing. The results are not directly comparable due to question wording differences.

¹³ Social grades A, B and C1 are the middle class socio-economic grades, whereas grades C2, D and E are the working class socio-economic grades. Please refer to Section 8.4 in the appendices for a fuller definition of social grades.

¹⁴ www.bl.uk/collection-items/new-perspectives-and-approaches-to-understanding-dementia-and-stigma-a-compendium-of-essays

¹⁵ 2017 Health, Ageing and Support Survey, Ipsos MORI research for the Department of Health and Social Care.

¹⁶ The results of this question are based on participants without a dementia diagnosis.

¹⁷ The results of this question are based on participants without a dementia diagnosis.

¹⁸ www.bsa.natcen.ac.uk/media/39130/bsa-33-attitudes-to-dementia.pdf

¹⁹ YouGov polling for Alzheimer’s Research UK 24 – 25 February 2016, Total sample size was 2,017 adults. The survey was carried out online. The figures were weighted and are representative of all GB adults (aged 18+).

²⁰ www.alzheimersresearchuk.org/about-dementia/types-of-dementia/alzheimers-disease/risk-factors and <https://www.thelancet.com/commissions/dementia2017>

²¹ www.bsa.natcen.ac.uk/media/39130/bsa-33-attitudes-to-dementia.pdf. The Dementia Attitudes Monitor uses an adapted version of the BSA risk factor question and surveys adults aged 15+, rather than 18+, as such results from the two studies are not directly comparable.

²² www.thelancet.com/commissions/dementia2017 and [www.thelancet.com/journals/lanneur/article/PIIS1474-4422\(14\)70136-X/abstract](http://www.thelancet.com/journals/lanneur/article/PIIS1474-4422(14)70136-X/abstract)

²³ A Quick Guide to Dementia, Alzheimer's Research UK www.alzheimersresearchuk.org/about-dementia/quick-guide-dementia-translations

²⁴ The base size for this question is less than 100 participants, as such the results should be regarded as indicative only.

²⁵ The results of this question are based on participants without a dementia diagnosis.

²⁶ NICE, Dementia: assessment, management and support for people living with dementia and their carers, June 2018 <https://www.nice.org.uk/guidance/ng97>

²⁷ In the European Attitudes to Alzheimer's Disease survey, participants were asked whether they would be willing to undergo a 'Cerebrospinal fluid test'.

²⁸ The results of this question are based on participants without a dementia diagnosis.

²⁹ 'Thinking differently: preparing today to implement new dementia treatments' a report by Alzheimer's Research UK, May 2018.

³⁰ Join Dementia Research www.joindementiaresearch.nihr.ac.uk

³¹ Orton, S. (1994), Evidence of the Efficiency of Quota Samples. Survey Methods Newsletter, vol. 15, no. 1; Stephenson, C. B. (1979), Probability Sampling with Quotas: Wan Experiment. POQ, vol. 43, no. 4.

³² Ibid.

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Alzheimer's Research UK is the UK's leading dementia research charity dedicated to making life-changing breakthroughs in diagnosis, prevention, treatment and cure.

Visit www.dementiastatistics.org/attitudes to find out more about the UK's understanding of, and perceptions towards, dementia.

www.alzheimersresearchuk.org



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