

# Dementia Attitudes Monitor

Shaping breakthroughs in public understanding of dementia and attitudes to research.

Summary report  
Wave 2 | September 2021



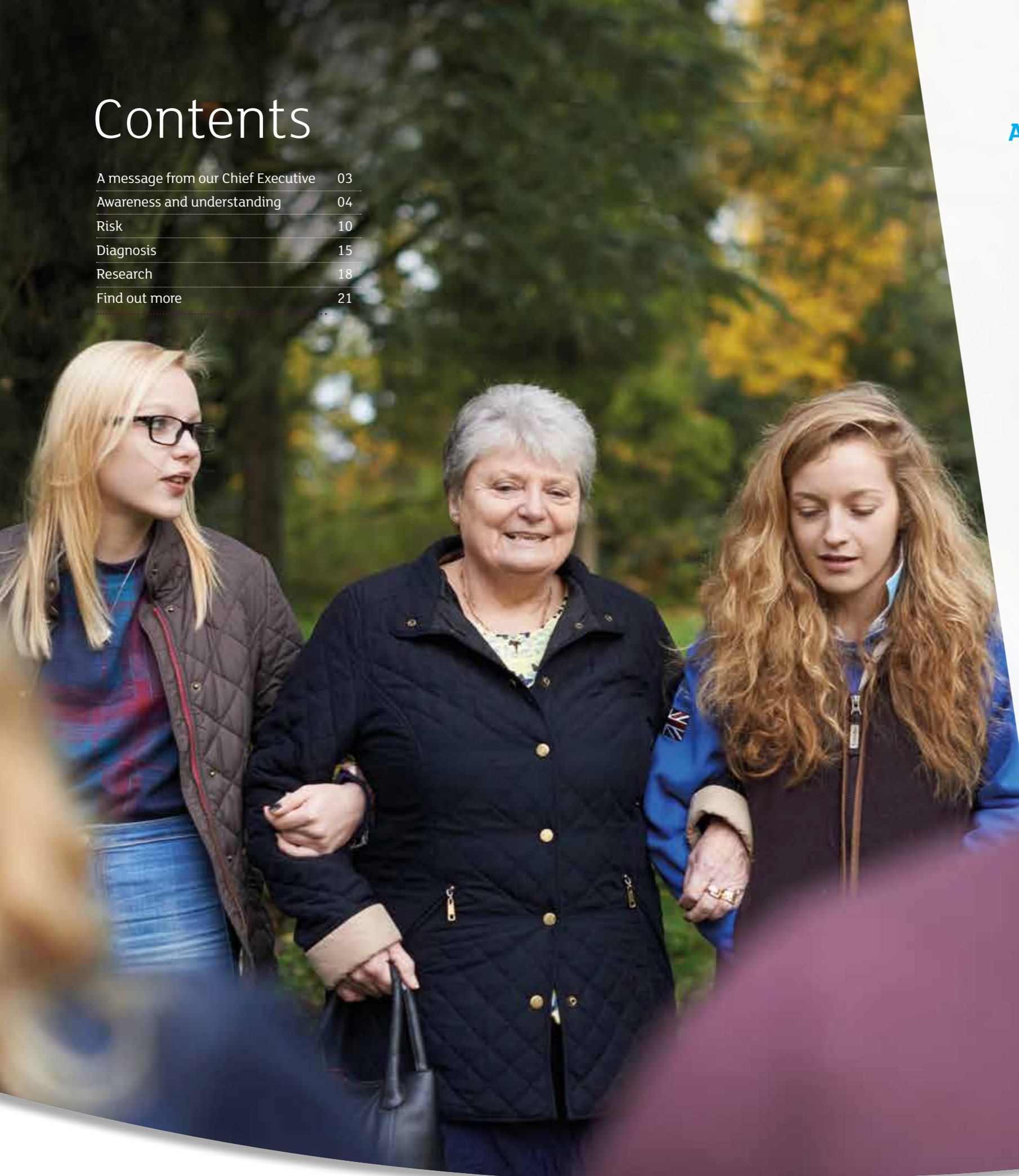
**Alzheimer's  
Research  
UK**

Make  
breakthroughs  
possible



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## A message from our Chief Executive



**By shining a light on the UK's attitudes towards dementia, the findings from Wave 1 of the Dementia Attitudes Monitor (2018) have been invaluable in informing activity across Alzheimer's Research UK and beyond – from designing awareness campaigns to keeping dementia research on the political agenda.**

Since Wave 1, the COVID-19 pandemic has had a profound effect on the lives of millions of people in the UK and across the globe. It has challenged the way we think about our health and thrust medical research into public consciousness like never before. This means now is an opportune moment to pause and re-evaluate, ensuring the decisions we make continue to reflect the UK's knowledge and ambitions for dementia research in the post-pandemic world.

For Wave 2 of the Monitor in 2021, the pandemic necessitated a change in methodology, with research moving from face-to-face interviews in participants' homes to telephone interviews. This meant adapting some questions, while also adding new ones to reflect the current dementia research landscape. Every effort was taken to ensure consistency - for example, using an interviewer-based approach rather than self-completion, so the findings from Wave 1 and Wave 2 of the Monitor remain comparable over time.

As we look to the future, I'm buoyed by Wave 2 findings showing that most people in the UK share our confidence that one day, the diseases that cause dementia will be cured, as well as a marked increase in willingness to take part in medical research studies that will help us achieve this vision.

Though in other areas, including understanding of our ability to influence our dementia risk and the different risk factors for the condition, there is still work to do.

Crucially, the Monitor helps us to unravel the links between different perceptions and attitudes. We know that those who have greatest understanding of dementia are more open to understanding their own risk and more willing to participate in medical research - underlining the importance of public awareness campaigns from charities and government as a driver of behaviour.

This Summary Report provides an overview of what the UK thinks and feels about dementia in 2021, highlighting both barriers to progress and the opportunities we must seize as we work to recapture momentum towards a world free from the fear, harm and heartbreak of dementia.

**For an even more comprehensive analysis, including a closer look at how factors such as age and ethnicity affect attitudes towards dementia, please visit [www.dementiastatistics.org/attitudes](http://www.dementiastatistics.org/attitudes)**

*Hilary Evans*

Hilary Evans  
Chief Executive, Alzheimer's Research UK





# Awareness and understanding

## More than half of us know someone who has been diagnosed with dementia.

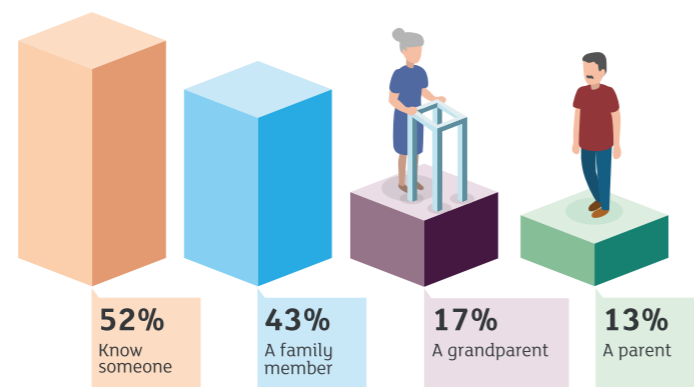
Dementia can be emotionally, physically and financially devastating for both the person living with the condition and those around them.

Wave 2 of the Dementia Attitudes Monitor has revealed that more than half (52%) of us in the UK know someone who has been diagnosed with the condition - a figure that remains unchanged since Wave 1 in 2018.

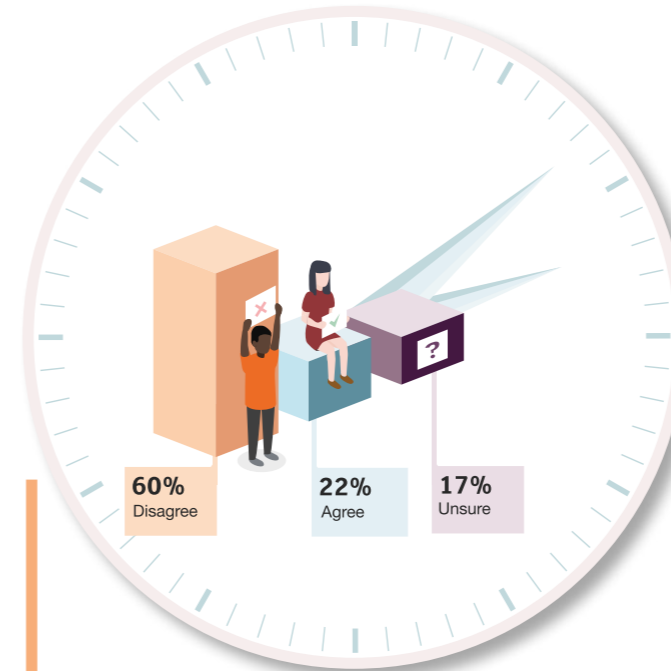
Most often, the person diagnosed is a grandparent (17%) or parent / step-parent (13%). And as age is the biggest risk factor for dementia, it's not surprising that older people were more likely to know someone with the condition (57% of 55-64 year olds).

The Monitor shows that having close personal experience strongly influences attitudes and understanding of dementia, with those who do not know someone who has been diagnosed being less likely to appreciate the true impact of the condition.

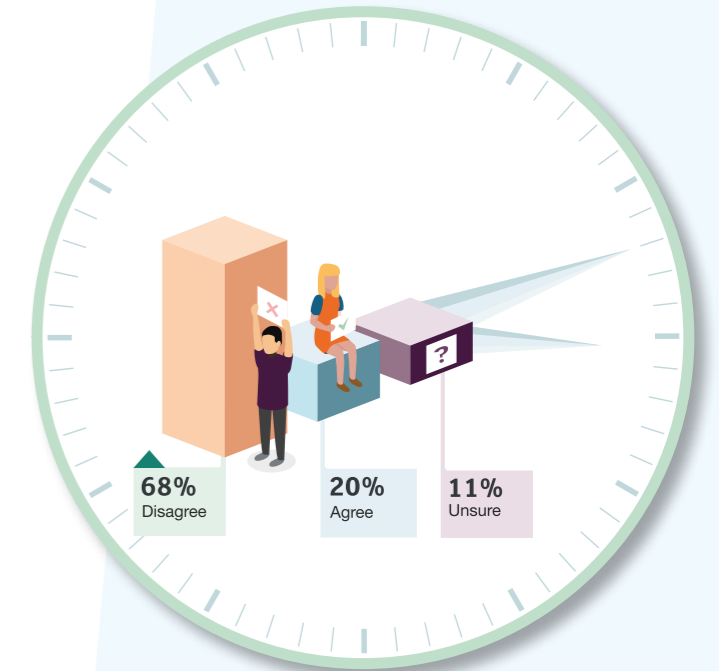
### 'Know someone with dementia'



### 'Dementia is an inevitable part of getting older'



2018



2021

### An increase in understanding of the diseases that cause dementia

Dementia is not a disease in itself, but a term used to describe a set of symptoms, including problems with memory, thinking, communication and movement.

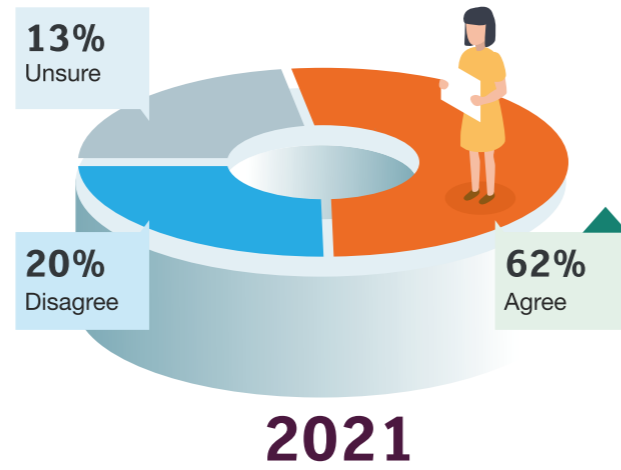
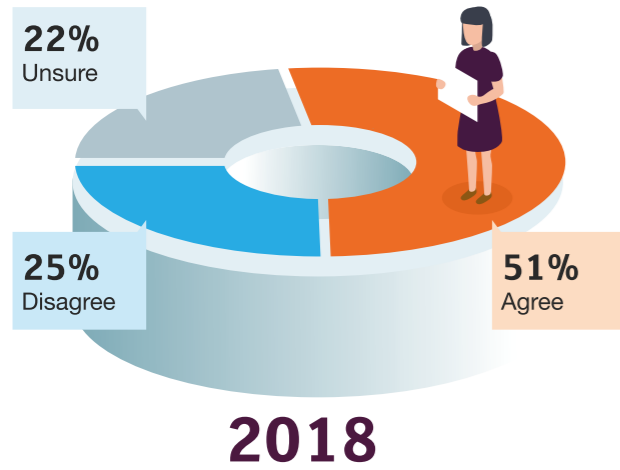
Rather than being a normal part of ageing, these symptoms are caused by complex diseases that affect the brain, most commonly Alzheimer's disease and vascular dementia.

This is recognised by the majority of people; 68% correctly disagree with statement '*Dementia is an inevitable part of getting older*' - up from 60% in Wave 1. This rise, combined with a drop in the proportion of people who are unsure whether dementia is inevitable (from 17% to 11%) suggests a positive shift in public understanding.





### 'Dementia is a cause of death'



Sadly, dementia is a progressive condition meaning a person's symptoms worsen over time, and excluding COVID-19, dementia has been the UK's leading cause of death since 2017. In Wave 1 of the Dementia Attitudes Monitor in 2018, just half (51%) of participants agreed that 'Dementia is a cause of death', but three years on,

62% recognised dementia as a cause of death, suggesting growing awareness of the terminal nature of the diseases that cause the condition.

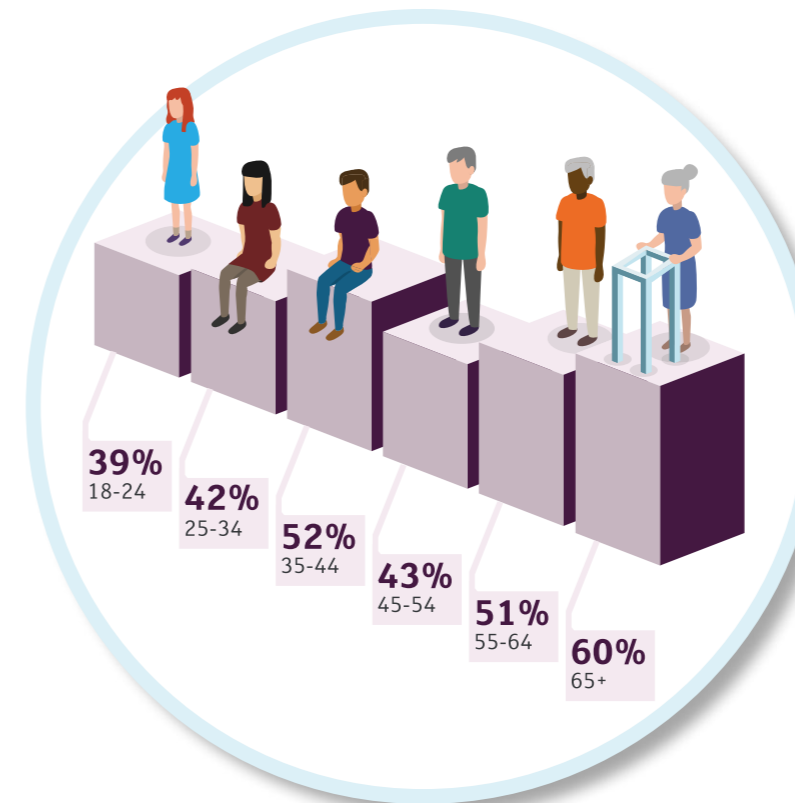
A significant increase can also be seen in the proportion who strongly agree with the statement, up from 18% in 2018 to 34%.

### Fear of dementia persists.

The COVID-19 pandemic had a profound effect on people with dementia and their families. During the peak of the pandemic, not only were many people living with dementia isolated from their friends and family, but death rates in those with dementia were more than double that experienced during pre-pandemic times.

It is not surprising that almost half (49%) of people say that dementia is the health condition they fear most about getting in the future, indicating an increase in concern since Wave 1 of the Monitor (42%).

### 'Dementia is the health condition I fear most'

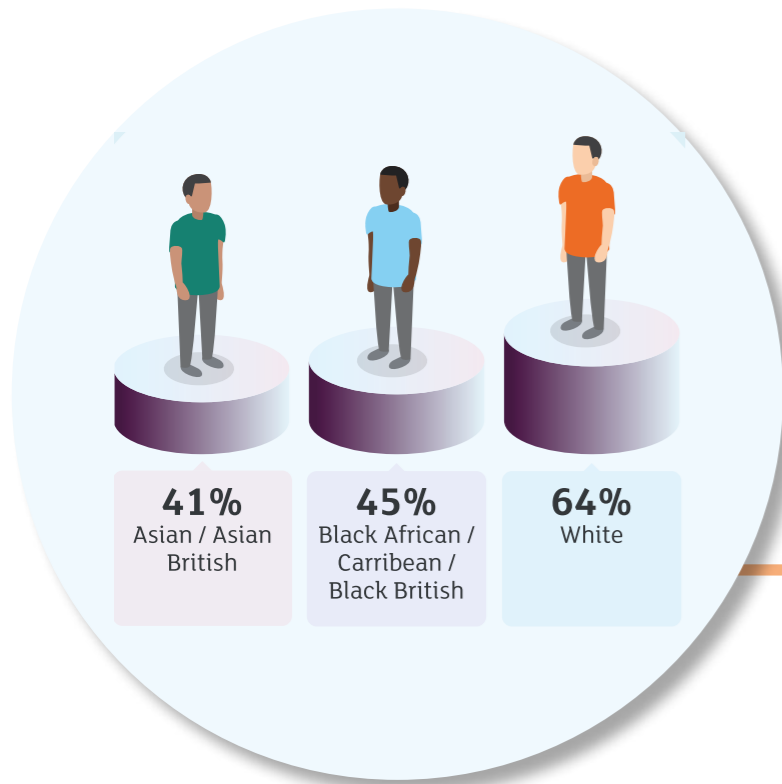


Reflecting the findings from Wave 1, women (55% compared to 42% of men) and older people (60% of those aged 65 or over) are more likely to agree with the statement 'Dementia is the health condition I fear most about getting in the future'. Those who know someone diagnosed with dementia (54% compared to 43% who have no experience of dementia) are also more likely to agree, suggesting that the challenges of supporting someone with dementia make a lasting impression on those around the person diagnosed.

Dementia-related stigma tends to stem from fear, alongside a lack of awareness and understanding about the condition, which can lead to a greater reluctance to engage with people with dementia.

Although two thirds (65%) of participants in Wave 2 disagree with the statement 'I would find it hard to talk to someone who has dementia', around a quarter (23%) of people agree. Men are more likely to find it difficult to talk to someone with dementia (28%, compared with 18% of women), along with those who have no experience of the condition (26% compared with 19% of people who have).





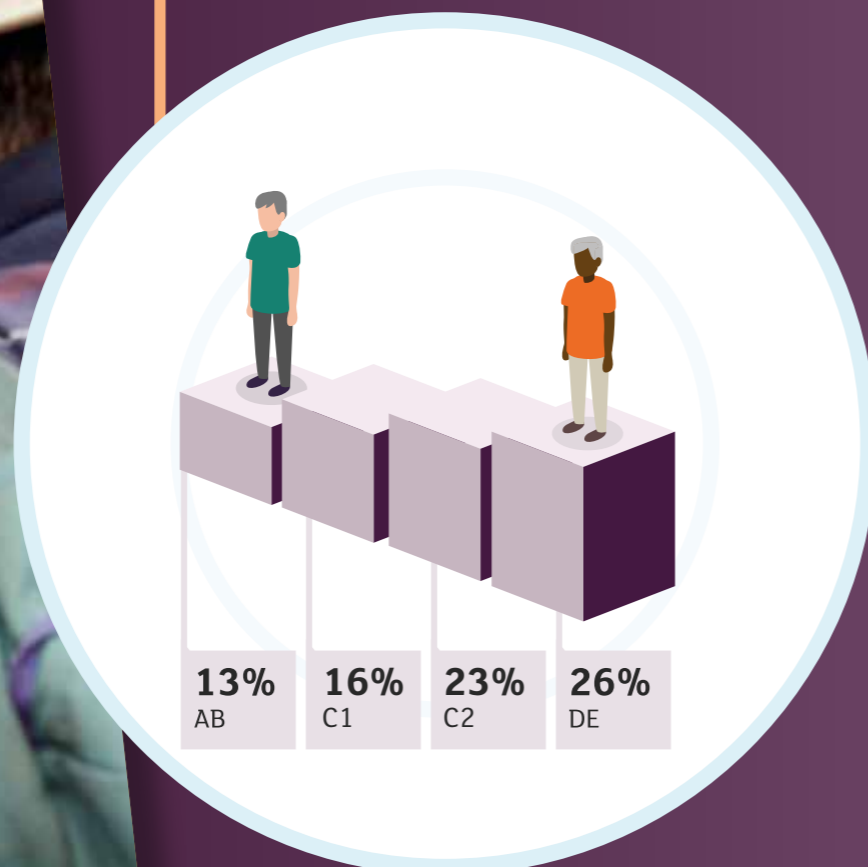
### Groups we must work harder to engage.

In addition to engaging those with no close personal experience of dementia, specific groups within society that must remain a priority include:

**Young adults:** Mirroring findings from Wave 1, those in the youngest age group (18 - 24) are much less likely to agree that dementia is a cause of death (45% agree compared to 62% overall and 72% of those aged 55 - 64).

**People who identify as Asian or Black:** People who identify as Asian/Asian British (41%) and Black African/Caribbean/Black British (45%) are less likely to agree with the statement 'Dementia is a cause of death' compared with those who identify as white (64%). Those who identify as black are also less likely to feel comfortable telling people about a diagnosis.

**People with lower socioeconomic status:** A quarter (26%) of those in social grades DE view dementia as an inevitable part of getting older, compared with 13% of people in social grades AB.



### Taking action

Despite the various challenges of the COVID-19 pandemic, dementia has never been far from the public consciousness in the past 18 months. This is largely due to the devastating toll of COVID-19 on people with dementia and their loved ones, as well as media coverage of high-profile figures' experience of dementia, including Dame Barbara Windsor who sadly died from Alzheimer's disease in December 2020 and Anthony Hopkins' Oscar-winning portrayal of the condition in the critically acclaimed film *The Father*.

These conversations, alongside continued campaigns that clearly articulate that dementia is caused by physical brain diseases and not a natural part of ageing, are helping to improve understanding of the nature of the diseases that cause dementia and their true impact.

It's reassuring that although the Monitor indicates an increase in fear of the condition, stigma in the UK remains low compared to global data from Alzheimer's Disease International's 2019 World Alzheimer's Report.

As understanding of dementia is the gateway to greater engagement around seeking a diagnosis, taking steps to reduce risk, and involvement in research, it's crucial that we continue to normalise conversations about the condition, paying special attention to key groups within society where greater misunderstanding remains.







# Risk

## Dementia risk awareness is still low.

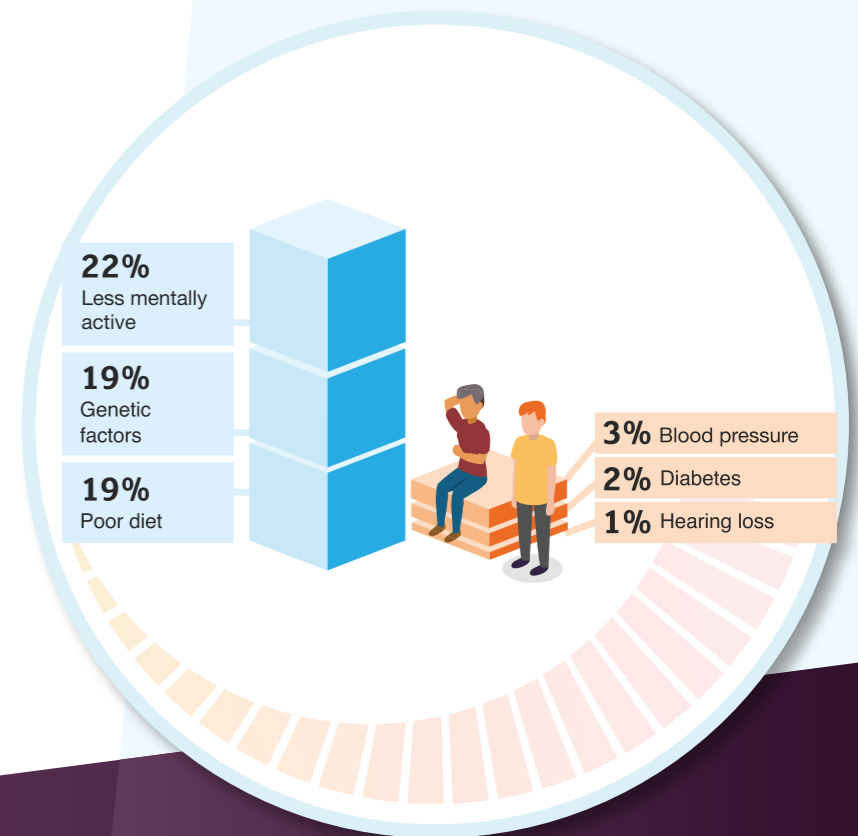
The latest evidence suggests that up to 40% of all cases of dementia are linked to factors we may be able to influence ourselves, including our diet, whether we smoke, and our levels of physical and mental activity. Yet the Monitor shows that just a third (33%) of UK adults think it's possible for people to reduce their dementia risk, a figure consistent with Wave 1 (34%).

Adults in both the youngest (18 - 24) and oldest (65+) age groups are less convinced that it's possible to reduce the risk of dementia (29% and 25% respectively), as are women (30% believe people can influence their dementia risk compared to 37% of men).

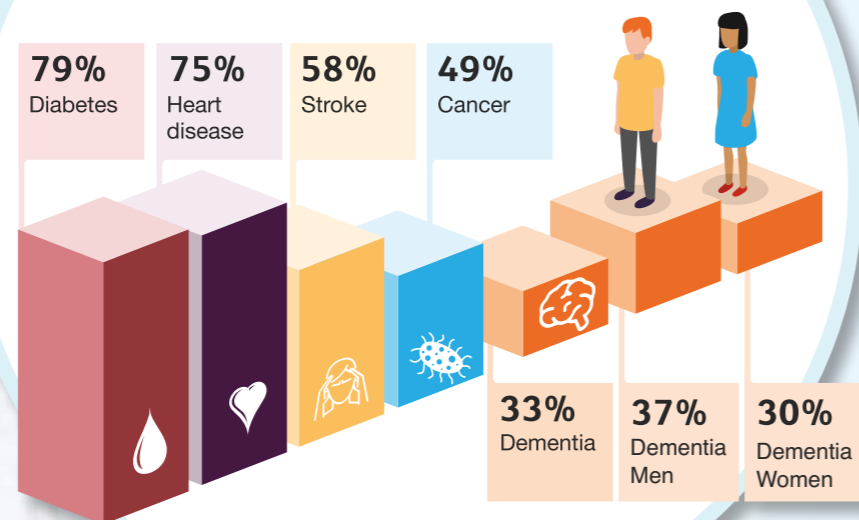
In addition to highlighting this limited awareness of the ability to reduce risk, the Monitor underlines the urgent need to build the UK's understanding of the risk factors for the condition.

When asked to consider what, if anything, could increase a person's risk, the most common, spontaneous, responses were 'being less mentally active' (mentioned by 22%), 'genetic factors' (19%) and 'poor diet' (19%).

## Awareness of dementia risk factors



## 'Which of these conditions can people reduce their risk of developing?'

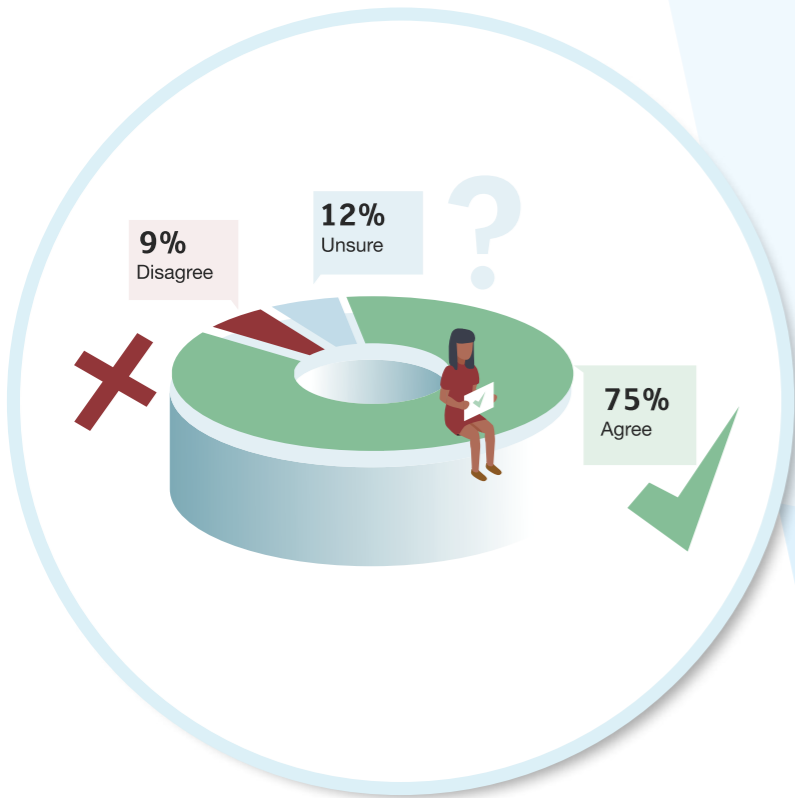


Only 9% of people in Wave 2 mentioned old age, 3% identified high blood pressure and 2% diabetes, though evidence suggests these are some of the factors most closely linked to dementia risk.

56% of UK adults weren't able to identify any of seven major risk factors from the 2015 British Social Attitudes survey (namely heavy drinking, smoking, high blood pressure, depression, diabetes and genetic factors, alongside the protective factor of taking regular exercise). This is higher than Wave 1 of the Monitor (48%) in 2018, and while not directly comparable, higher than the 22% recorded in the 2015 British Social Attitudes survey.



**'It is possible to influence brain health'**



**Protecting brain health - a major opportunity.**

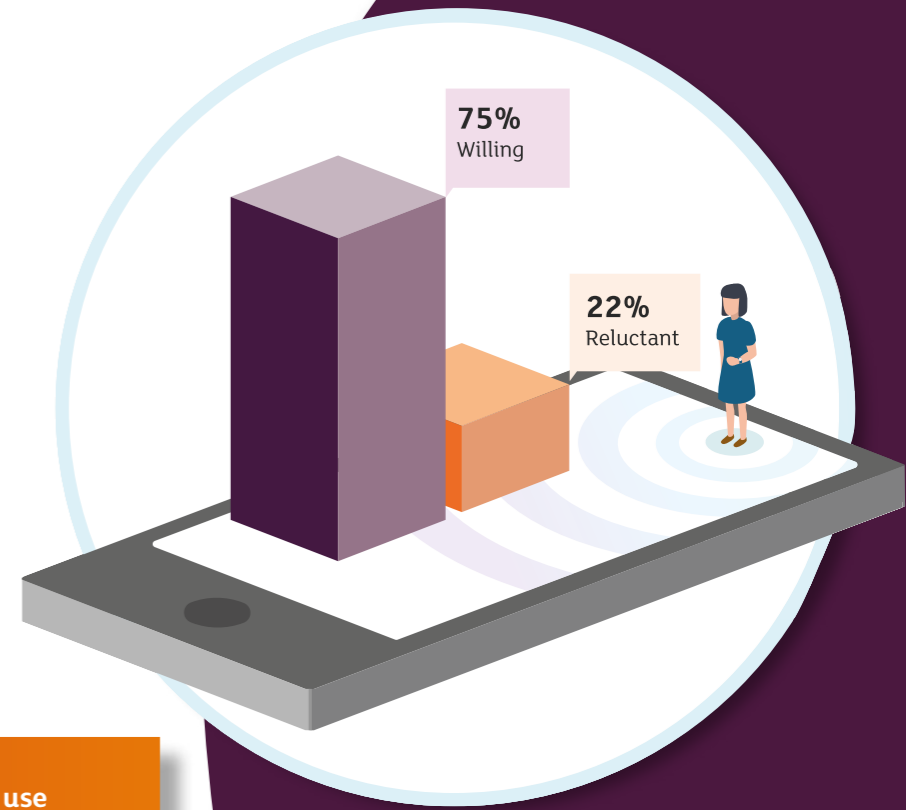
Despite limited understanding of the ability to reduce the risk of developing dementia, three quarters (75%) of people believe it's possible for a person to influence their brain health.

In fact, seven in ten people (70%) who do not think it's possible to reduce the risk of developing dementia, agree that it is possible to influence brain health. This finding reinforces our previous research with the Royal Society for Public Health suggesting that positively reframing dementia risk reduction as protecting brain health presents a major opportunity to increase engagement and transform public attitudes and outcomes.

**Openness to using wearables to better understand dementia risk.**

In response to a rapid expansion of the availability and use of wearable devices, such as smartwatches, and health-related apps since Wave 1, we introduced a new question to investigate the potential for using such devices to pick up early signs of disease.

Three quarters of people (75%) would be willing to use smartphone apps and wearable technology to help themselves and their doctor better understand their brain health and future risk of dementia.



The Monitor shows that reluctance to use technology in this way increases uniformly from youngest to oldest age groups, and is significantly higher among those who never use the internet (51% are reluctant compared to just 19% of those who use the internet every day).

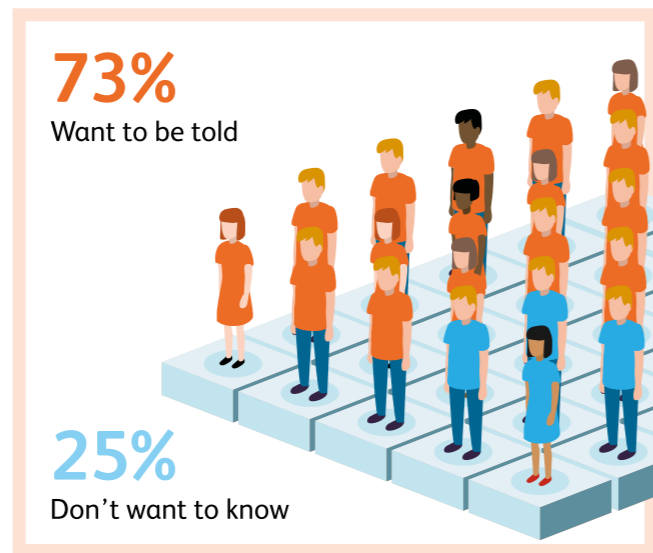
**'Willing to use apps and wearable tech to understand risk'**

**'Would want to know their risk of developing dementia'**

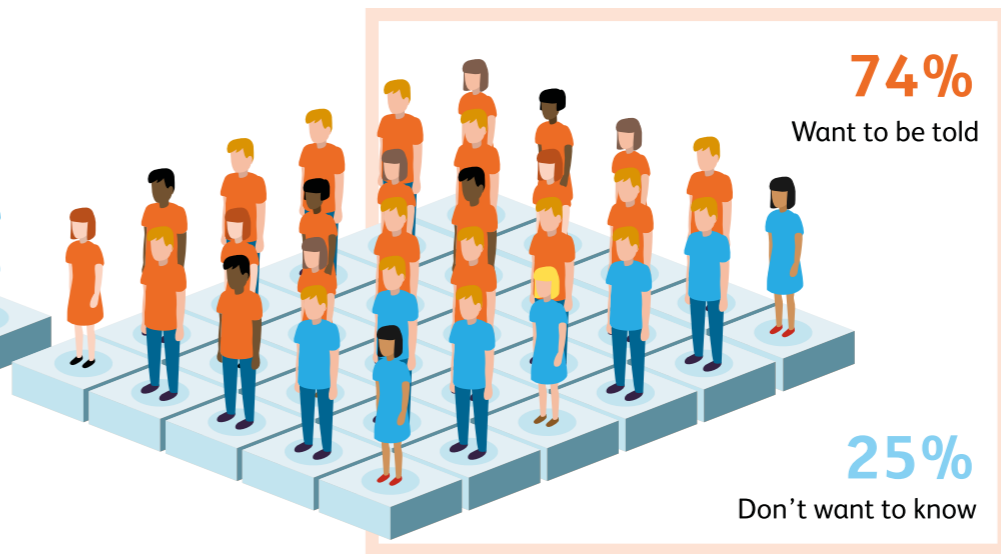
**2018**

**Public appetite for information on personal dementia risk remains strong.**

The majority of UK adults (74%) say they would want to be told in midlife about their personal risk of developing dementia later in life based on their genetics and / or lifestyle, if their doctor could provide this information (73% in Wave 1).



**2021**



Of these people, 52% say 'Yes, definitely' – up from 47% in 2018 and 22% say 'Yes, probably'.

The groups most reluctant to know about their own risk of developing dementia in later life are those aged 55 and above (30% would not want to know compared to 22% of 18 - 24-year-olds and those who identify as white.



## Taking action

Raising awareness of the actions people can take to reduce their personal risk of developing health conditions, including dementia, is a key area of focus for charities, public health organisations and government.



The Dementia Attitudes Monitor highlights a clear gap in public understanding regarding both the ability to reduce dementia risk and the steps that can help do so. Joined-up action to tackle this gap promises to have a significant impact on the number of people affected by dementia at a population level.

Campaigns like Alzheimer's Research UK's Think Brain Health, which has already seen more than 2 million people engage on social media, as well as Brain Health Scotland, Be Brain Powerful in the US and the collaborative Global Council on Brain Health

are all essential in building understanding of the steps we can take at an individual level to help reduce our risk.

Other risk factors, such as air pollution and traumatic brain injury, are difficult to avoid as individuals, but can be addressed through wider societal change. That's why we're asking government to work with us to develop a national brain health strategy, as well as new educational resources for health care professionals to help them support their patients in the best way.

## Supporter story

“ Sadly, several of my mum's siblings have Alzheimer's disease. One of my uncles died in his late 70s and another was diagnosed eight months ago, but thankfully doing quite well at the moment. My aunt has been bedridden for the last four years. They are all based in India, and Mum, now 70, is very anxious that that she might also develop dementia.

I think awareness and understanding of the diseases that cause dementia needs to improve in my community. Too many people believe that it is just memory loss and a normal part of old age.

I find it reassuring that there are things that we can do to help protect our brain health, such as practising numbers and taking regular exercise.

This is why I am passionate about spreading awareness within my family and my community. ”

Akanksha Kulkarni



# Diagnosis

## Majority would seek a formal diagnosis of dementia.

A formal diagnosis of dementia is the gateway to treatments, support and care services, and opportunities to get involved in pioneering research studies. However, it's estimated that less than two-thirds of people in England with dementia have received a formal diagnosis.

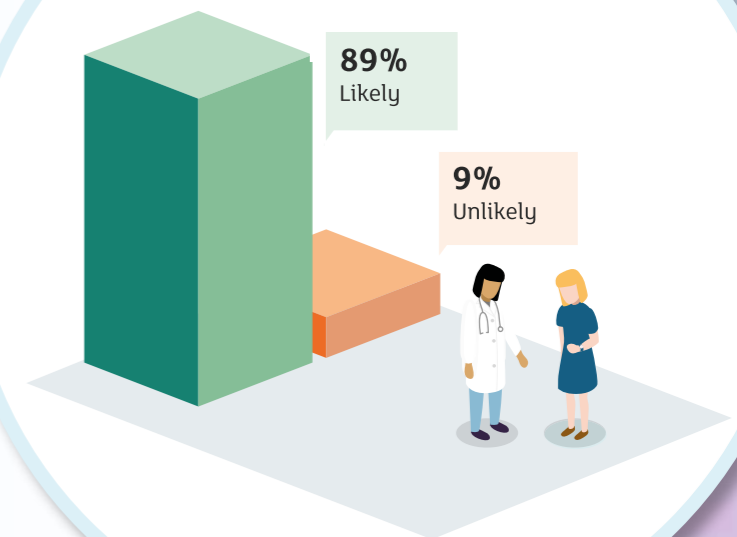
In 2018, we found that the vast majority of people (82%) agreed that there is value in being given a formal diagnosis. In light of the COVID-19 pandemic and a significant drop in dementia diagnosis rates during 2020, we evolved this question to explore people's willingness to seek a diagnosis if they were concerned that they might be in the early stages of Alzheimer's or another form of dementia. Reassuringly, an even greater number (89%) say they would be likely to seek a formal diagnosis and just 9% would not.

There were two primary motivators for seeking a diagnosis - to allow access to treatments that could help and to enable the person concerned to plan for the future (each mentioned by 32% of participants).

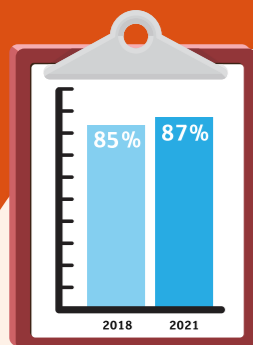
Although there are no treatments to stop or slow the diseases that cause dementia available in the UK today, there are interventions that doctors can provide to help manage symptoms. One of the main reasons for reluctance to seek a formal diagnosis, mentioned by 14% of participants, is that 'there are no treatments that can really make a difference', pointing to an opportunity to raise awareness of the treatment options currently available.

Surprisingly, nobody mentioned concerns about COVID-19 and despite the challenges of the pandemic on NHS services, only 4% mentioned concerns about their doctor not being available.

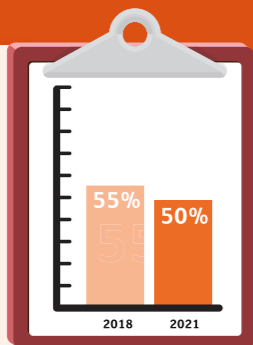
## 'Likely to seek a formal diagnosis'



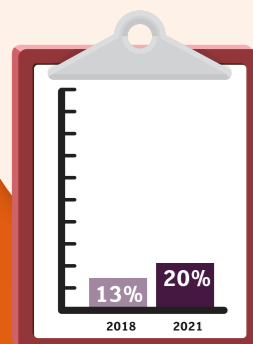




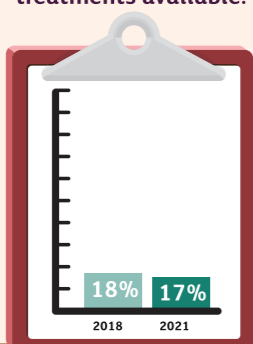
Would take the test



Would take test regardless of the effectiveness of treatments available.



Would take test if they could be offered an effective treatment.



Would take test if they could be offered an effective prevention.

## The public is open to advances in pre-symptomatic detection of the diseases that cause dementia.

Today, the diseases that cause dementia are diagnosed when symptoms like memory loss begin. But to stand the best chance of slowing or stopping them, we need to intervene years earlier, before irreversible damage is done.

The Monitor explores the UK's attitudes towards shifting the point of diagnosis earlier, finding that most people (87%) 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 any symptoms appeared. This is consistent with the 2018 Wave 1 survey findings (85%).

There are caveats to this, with one in six people (17%) indicating that they would only take the test if they could be offered an effective prevention and one in five (20%) only doing so if they could be offered effective treatment. Half (50%) would take the test regardless of the effectiveness of treatments available.

In a year that has seen mass testing and vaccination programmes rolled out across the world, the Monitor shows strong and growing willingness to undergo several different clinical tests to make an accurate and early diagnosis. Some of these are currently used and others may be used in future e.g. blood and eye tests.

Appetite for using technology to help make an accurate and early diagnosis is similarly strong, with three quarters (75%) willing to use computer or smartphone tasks or apps that monitor day-to-day life and 77% willing to use wearable technology for this purpose.

## Taking action

At the height of the pandemic, the NHS was put under enormous pressure, with many services and clinicians having to shift the focus of their work to support wider COVID-19 efforts or adapt to new ways of working including operating remotely.

While dementia diagnosis rates fell steadily during this time, it's reassuring that the Monitor shows that the majority of people would seek a formal diagnosis in 2021 if they were concerned they might be in the early

stages of the condition, and there is little evidence to suggest the pandemic has increased reluctance to do so.

It's important that efforts to encourage the public to seek an accurate and timely diagnosis resonate with key groups in which reluctance is greatest - particularly older adults and those with no formal qualifications.

And as our Early Detection of Neurodegenerative diseases (EDoN) initiative gains pace -



aimed at using wearable technology to pick up early signs of disease long before they can be spotted by the human eye - we are spurred on by the UK's openness to using such innovative techniques.



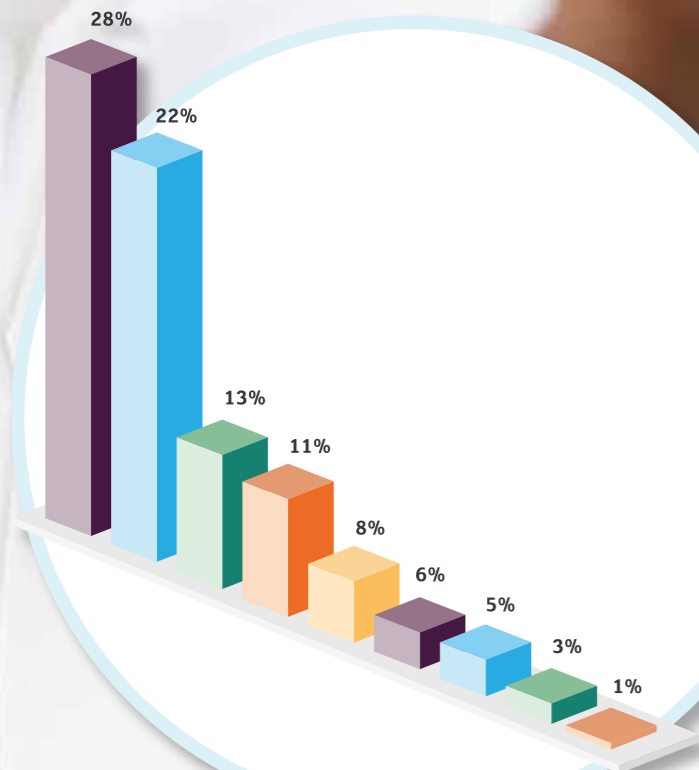


# Research

## Finding a cure is still the UK's top research priority.

Many different types of research have the potential to improve the lives of people with dementia and those around them.

The Monitor once again identified strongest support for medical research into ways to cure the diseases that cause dementia, cited as the most important type of research by 28% of participants. Next, research into ways to prevent the disease was chosen as most important by 22% of people, findings that are consistent with Wave 1.



## Priorities for medical research

- Research for a cure (28%)**
- Research for ways to prevent the disease (22%)**
- Research for new forms of medication to stop the disease (13%)**
- Research for ways to improve quality of life through better care (11%)**
- Research for ways to diagnose the disease earlier (8%)**
- Research for new forms of medication to slow the disease (6%)**
- Research for non-drug treatments and therapies to help manage symptoms (5%)**
- Research for new forms of medication to help with symptoms (3%)**
- None of these (1%)**

## There is belief that one day the diseases that cause dementia will be cured.

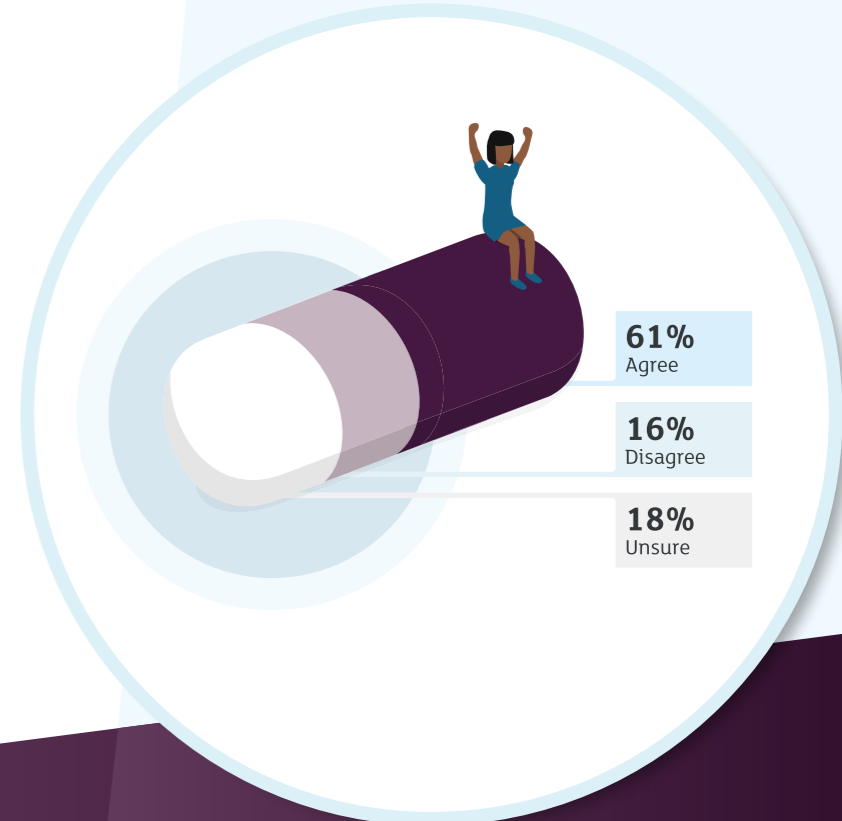
Wave 1 of the Dementia Attitudes Monitor revealed uncertainty around current treatments for dementia – only 27% of people felt that current treatments were effective with one in five (22%) being unsure.

In 2021, we built on these findings, exploring people's belief in the potential for research to deliver cures for the diseases that cause dementia.

Positively, the majority (61%) of UK adults believe that one day the diseases that cause dementia will be cured; 18% express uncertainty and just 16% disagree.

Approaching three-quarters (72%) of people aged 65 and over agree that the diseases that cause dementia will be cured (compared with 55% of 18-24-year-olds) – the age group least likely to think it's possible to reduce dementia risk.

## 'One day the diseases that cause dementia will be cured'



## A boost in willingness to take part in medical research.

Set against the backdrop of over half a million people across the UK taking part in research into the effects of, and treatment for, COVID-19 and the publicity surrounding this research, the Monitor found that the majority (69%) of UK adults would now consider getting involved in medical research for dementia. This represents a marked increase since Wave 1 (50%).

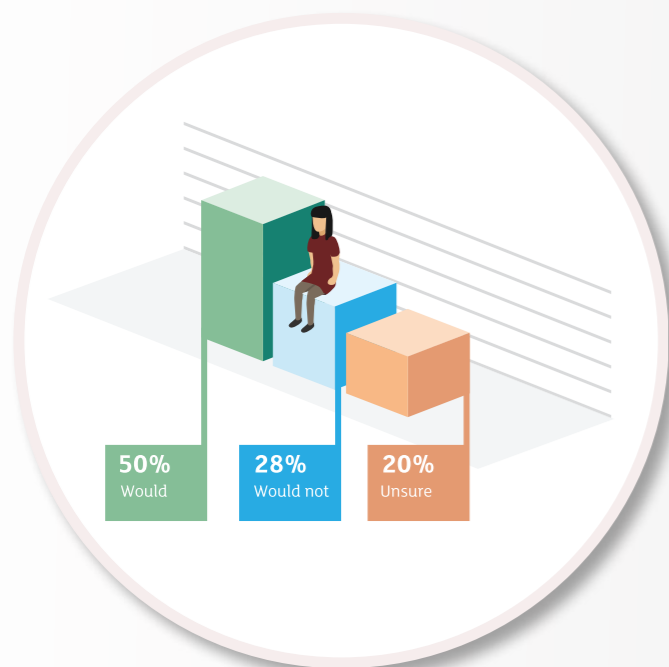
17% say they would not be willing to participate and 13% are unsure - both down from 20% and 28% respectively in 2018.

By age, the Monitor shows that willingness to get involved in research is highest among those aged 25 - 34 (75%) and lowest among those aged 65+ (57%), where there is arguably the most to learn about the condition.

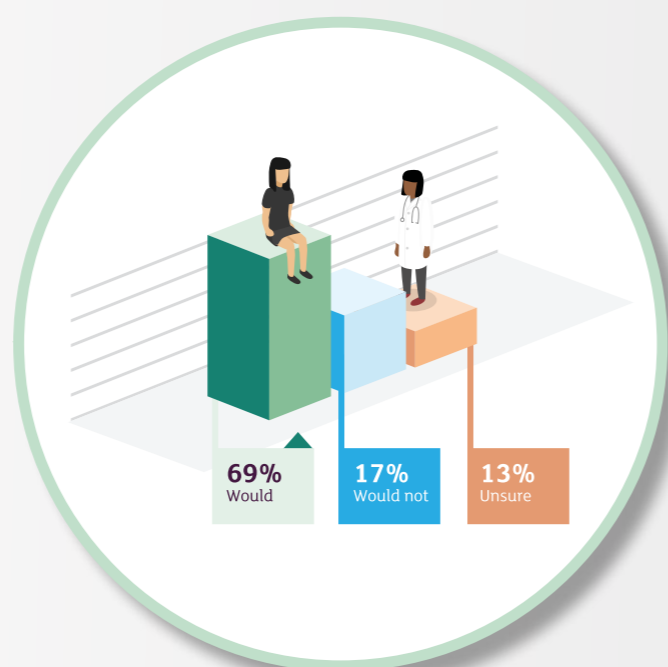




## 'Would be willing to participate medical research for dementia'



2018



2021

### Willingness to participate also varies significantly by:

**Education level** - 28% of those with no formal qualifications are not willing to get involved compared to 11% of those educated to degree level.

**Experience of dementia** - 21% of those who have no personal experience of dementia are not willing to get involved compared to 13% of those who do.

**Ethnicity** - 61% of people from Black, Asian and minority ethnic groups would be willing compared with 71% who identified as being from a white ethnic group. For this question, it was not possible to detect differences within specific ethnic minority groups due to sample size limitations.

'Research is the only answer to dementia' is the main motivator, cited by 46% of those expressing an interest in taking part. Witnessing a family member or friend living with the condition is also a key motivator, mentioned by 23% of participants. Positively, over one in ten (12%) say they have seen the importance of medical research during the COVID-19 pandemic, with this being a particular motivator for younger people (20% of 18 - 24-year-olds).

As seen in Wave 1, uncertainty about what would be involved is the primary reason for not being willing to take part in research studies, mentioned by 23% of those who would not participate. This is followed by not having enough time (20%). 12% say that the idea of taking part in medical research is too intimidating, suggesting that there's more to be done in terms of communicating both the benefits and the practicalities

## Taking action

The UK public's ambitious priorities for dementia research - to find preventions and cures for the brain diseases that cause the condition - and confidence that research will ultimately deliver them, further strengthen our cause. We continue to campaign for government to deliver on its 2019 manifesto commitment to double dementia research funding to £160 million a year.

Research towards new treatments for dementia is advancing at pace, with over 240 potential new treatments now in clinical trials. During 2020, we also saw the drug aducanumab approved for use in the US - the very first drug aimed at slowing down Alzheimer's disease rather than just helping with symptoms.

It's essential that we leverage growing public interest in, and support for, medical research by empowering more people to participate.

In the UK, people with dementia and healthy volunteers can register to be matched with studies taking place online or in their area through Join Dementia Research (JDR) - a partnership between Alzheimer's Research UK, Alzheimer's Society, Alzheimer Scotland and the National Institute for Health Research. Nearly 16,000 people enrolled in studies in 2020, more than in any previous year, though JDR registrants from minority ethnic backgrounds remain low. It is essential that we support people from diverse backgrounds to



volunteer for studies, as well as ensuring the infrastructure is in place to support clinical trials, especially for those in the earliest stages of disease.

And as the groups within society with the lowest levels of understanding of dementia are also those most disengaged with research efforts, we will continue to drive up the UK's knowledge around the condition through major awareness campaigns including #ShareTheOrange, Dementia Uncovered and Think Brain Health, which reach millions of people each year.

## Supporter story

“When I got my diagnosis of posterior cortical atrophy (PCA) at the age of just 56, it meant that I was unable to work anymore - the impact felt like dropping off a cliff. Before my diagnosis I didn't know what PCA was, so it came as a bit of a shock. Even my GP had not previously heard of it.

With this rare form of dementia, it is very important to me to be able to take part in research and I think we need to make more people aware of the role they can play. I have taken part in different types of research, including clinical trials and one-off and long-term observational studies. I have taken practical tests and have had ultra high resolution brain scans.

I have found great comfort and solace in the fact that the clinical trial I'm involved in carried on during the COVID-19 pandemic. Making the 200-mile each way round trip to London from my home in Cheltenham to take part in the research played a significant role in keeping me motivated and mentally resilient during lockdown.

Having just completed Stage 2 of the trial I am looking forward to getting involved with the next stage and getting going as soon as possible. I am testament to the fact that research is offering hope for people living with all forms of dementia, including rarer diseases like PCA, and this is why I support Alzheimer's Research UK in their mission to make breakthroughs possible.”

Doug Banks





# Find out more

The following resources provide further information about dementia and the topics covered within this report:



## Full Dementia Attitudes Monitor Report (Wave 2)

Read the full Wave 2 Dementia Attitudes Monitor Report for a comprehensive analysis of UK attitudes towards dementia and research:

[www.dementiastatistics.org/attitudes](http://www.dementiastatistics.org/attitudes)



## Wave 1 Report

Read the first Dementia Attitudes Monitor Report (research conducted in 2018):

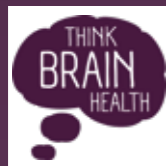
[alzres.uk/DAM-wave-1](http://alzres.uk/DAM-wave-1)



## Early Detection of Neurodegenerative diseases (EDoN)

With a wealth of digital data at our fingertips, now is the time to transform the early detection of the diseases that cause dementia. Learn more about our game-changing EDoN initiative:

[edon-initiative.org](http://edon-initiative.org)



## Think Brain Health

We want everyone to know the key ingredients to good brain health and feel empowered to act on that knowledge. Find out how taking positive steps can help reduce dementia risk:

[alzres.uk/think-brain-health](http://alzres.uk/think-brain-health)



## An introduction to dementia

Our 'Quick guide to dementia', available in English and eight other languages, provides the basic facts about dementia in easy-to-understand terms:

[alzres.uk/quick-guides](http://alzres.uk/quick-guides)



## Alzheimer's Research UK would like to thank all those who took part in the survey or shared their experiences and insights in the drafting of the report.

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THE PERFUME SHOP

For more information, please contact the Communications team using [attitudes@alzheimersresearchuk.org](mailto:attitudes@alzheimersresearchuk.org) or 0300 111 5 666.

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Research was carried out by Ipsos MORI on behalf of Alzheimer's Research UK. Ipsos MORI surveyed a nationally representative quota sample of 2,259 adults in the United Kingdom aged 18+, using its Telephone Omnibus (Computer Assisted Telephone Interviewing) between 18 June and 19 July 2021. There was also an ethnic minority boost within this resulting in a total sample of 387 adults from an ethnic minority background.

Data has been weighted to the known national population proportions for age within gender, government office region, working status and social grade.

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.



Alzheimer's Research UK  
is the UK's leading dementia  
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