

Dementia Attitudes Monitor

Wave 1 2018

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



**Alzheimer's
Research
UK**

Make
breakthroughs
possible

Contents

A message from our Chief Executive	03
Awareness and understanding	04
Risk	09
Diagnosis and treatment	12
Research	16
Find out more	19



A message from our Chief Executive

As the UK's leading dementia research charity, Alzheimer's Research UK funds research that will help us prevent, treat and one day, cure dementia. 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. The Wave 1 results include data from 2,361 interviews conducted by Ipsos MORI between 15 June and 5 July 2018.

It is a sad truth that more people are affected by dementia than ever before. As the first wave of 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 work to do to improve understanding of the diseases that cause it. Making breakthroughs in public understanding has the potential to empower more people to take steps to maintain their own brain health, to seek a diagnosis and to support research that has the power to 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.

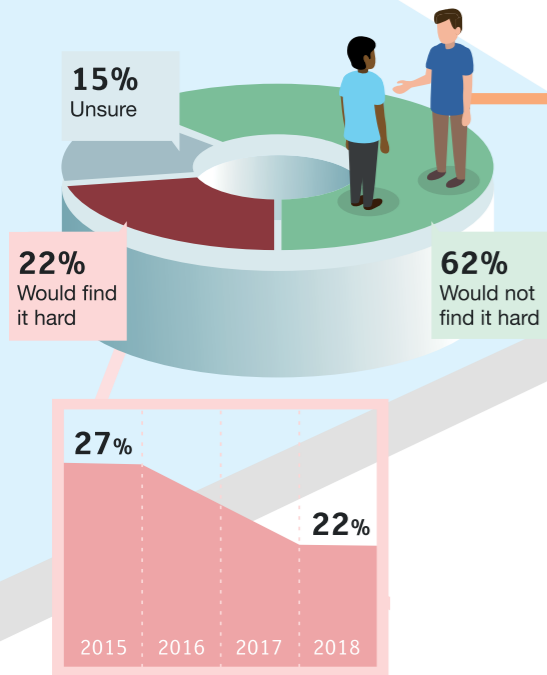
This Summary Report provides an overview of the headline statistics from the Monitor, our key takeaways and the steps we are taking in response to the findings.

For an even more comprehensive analysis of the UK's attitudes towards dementia, including a closer look at how factors such as age and ethnicity affect attitudes towards dementia, please visit www.dementiastatistics.org/attitudes

Hilary Evans



'Would find it hard to talk to someone who has dementia'

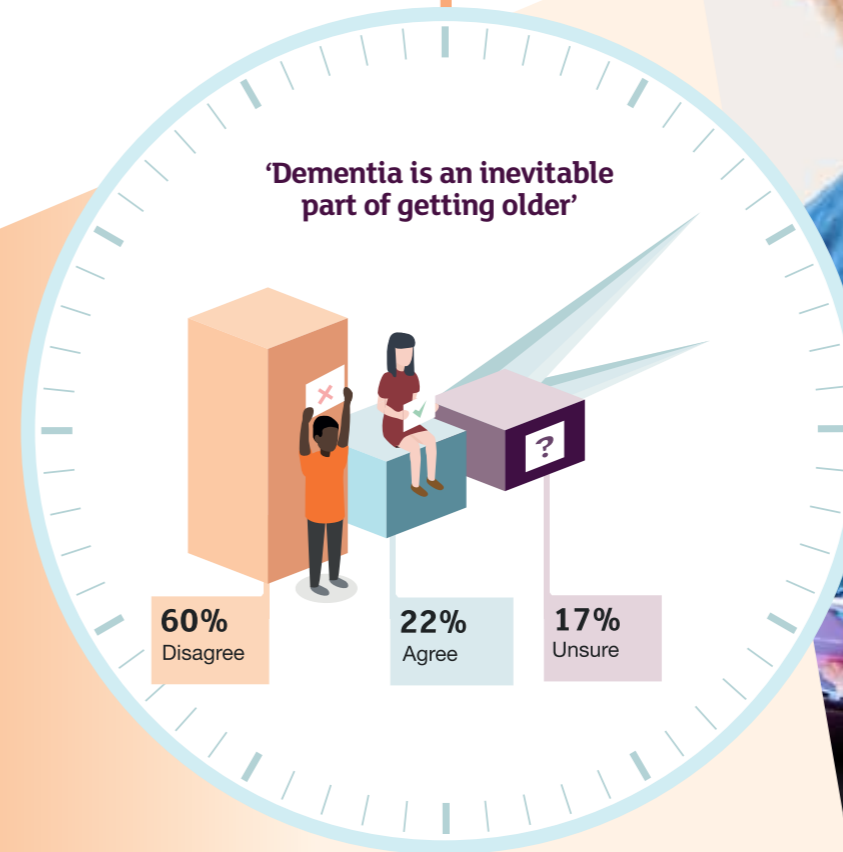
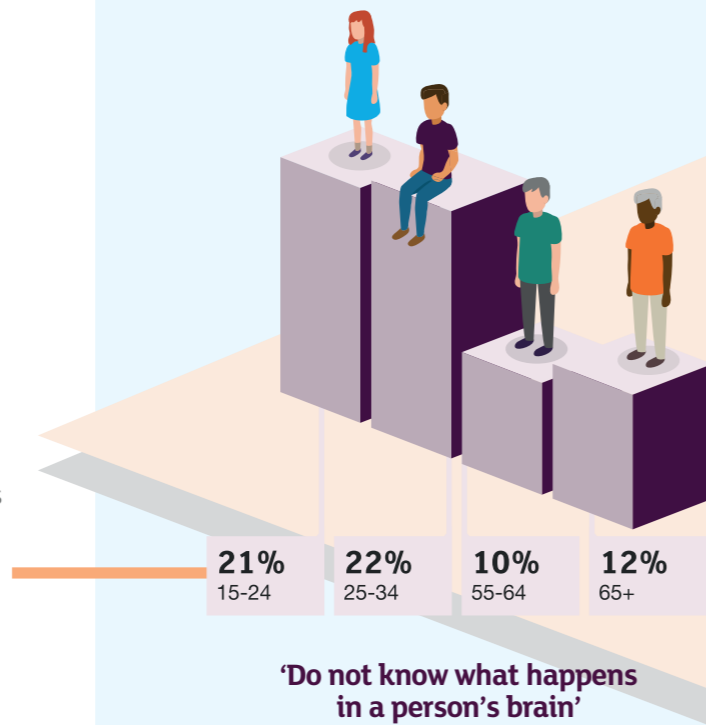


Although two in five people named dementia as the health condition they feared most (42%), the results from the Monitor show little evidence of specific groups of people that harbour stigma towards dementia. Just over one in five people (22%) agree that 'I would find it hard to talk to someone who has dementia', while around three in five people (62%) disagree. This is compared to 27% agreeing with the statement in 2015 as part of NatCen's British Social Attitudes Survey. This suggests modest improvements in public acceptability and awareness of dementia in recent years.

Over half (60%) of UK adults rightly disagree with the statement that 'dementia is an inevitable part of getting older', however one in five (22%) still incorrectly agree. This shows that we must work harder to improve understanding that brain diseases cause dementia.

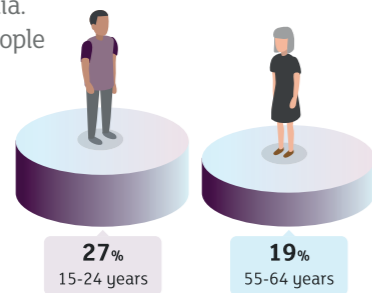
Understanding of the diseases behind dementia remains low

When asked to describe what happens in a person's brain when they get dementia, common responses included 'disease' and 'degeneration'. 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 to one in 10 people aged 55-64 (10%) and 65 or over (12%).

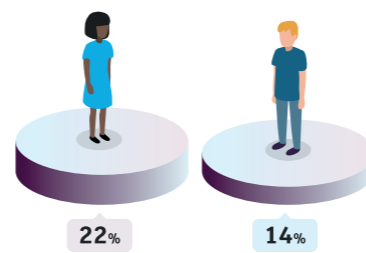


Groups we must work hard to engage

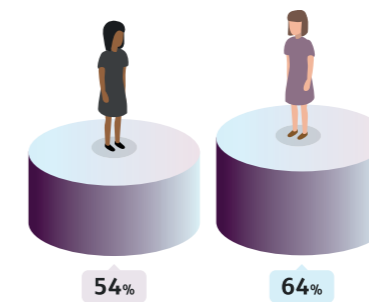
Younger adults are less likely to have been affected by dementia. Over a quarter of people aged 15-24 agree that dementia is an inevitable part of getting older compared with 19% of those age 55-64.

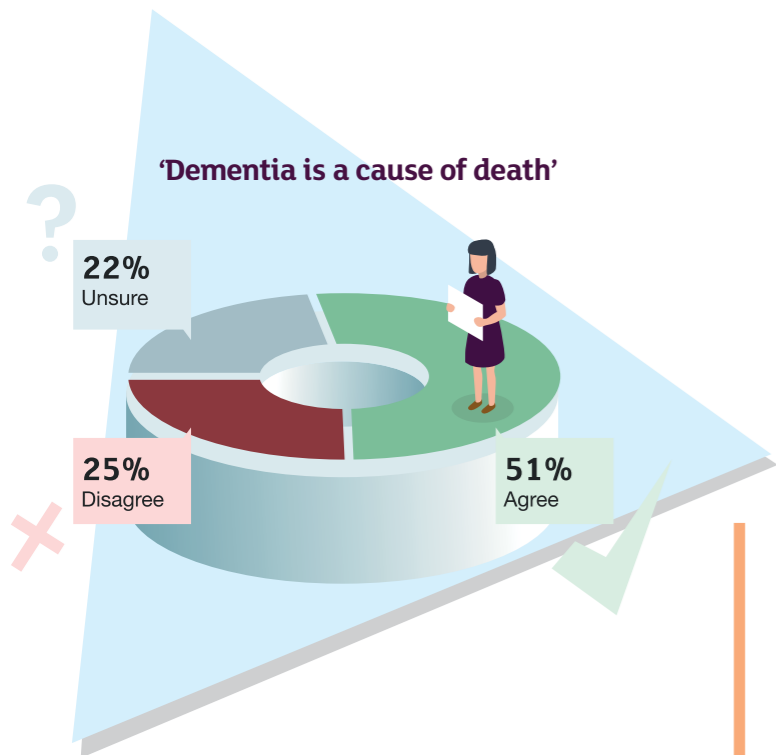


Those from black, Asian and minority ethnic backgrounds are less likely to recognise dementia as a cause of death (40%) compared to those from a white ethnic group (53%) and more likely to say they do not know what happens in a person's brain to cause dementia (22% compared with 14% of those who are white).



Those with no experience of dementia are less likely to feel comfortable telling people outside their close family if they were diagnosed with dementia (54%) than those who have known someone with dementia (64%).





The diseases that cause dementia can have a striking physical, as well as mental, impact on the human body, particularly as they progress. Although the vast majority (93%) of those interviewed agreed that 'dementia affects mental aspects of a person's health', 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 with the statement entirely.

Just half (51%) of the public recognises that dementia can cause death, despite Alzheimer's disease and other dementias now being the leading cause of death in the UK, accounting for more than 12% of all deaths.

Taking action

We must continue to normalise the conversation about dementia, sharing the varied experiences of those affected and taking collective responsibility to ensure the accurate portrayal of dementia across the media, arts and popular culture.

Charities and other dementia-relevant organisations must communicate the seriousness and physical nature of the diseases that cause dementia, as well as the hope that can be drawn from research. We must work hard to engage younger generations with the realities of dementia and ensure that our messages are delivered in a way that is inclusive to those in black, Asian and minority ethnic communities.

Reducing the number of people who believe that dementia is an inevitable part of ageing is key, as this belief drives other negative attitudes towards dementia. Our findings show that those who believe dementia is an inevitable part of ageing are less likely to see the value in seeking a formal diagnosis and are less likely to engage with research developments that could bring about life-changing treatments and ultimately, a cure.

Case study

“ Although it's often thought of as a disease of older people, around 5% of people with Alzheimer's in the UK are under 65.

In May 2015, my Dad became one of those people when he 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



Risk

An individual's risk of developing dementia is made up of different factors including age, genetics and lifestyle. Research has shown that some of the factors that increase a person's risk of developing dementia are the same risk factors for cardiovascular disease, including high blood pressure and obesity.

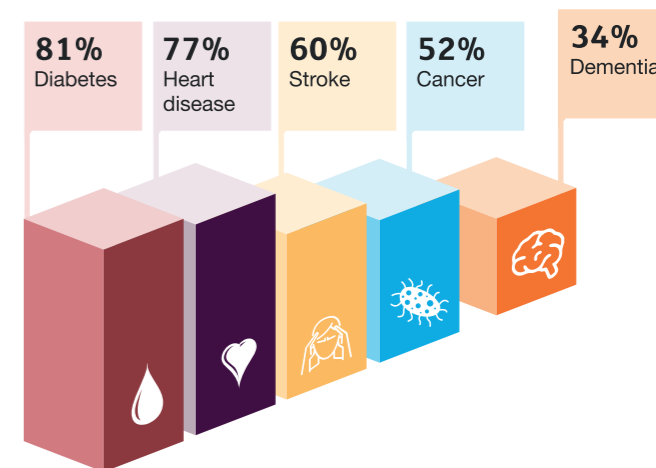
Public awareness of dementia risk remains low

Despite growing evidence of modifiable risk factors for dementia, and its inclusion in recent public health messaging such as Public Health England's 'One You' campaign, the Dementia Attitudes Monitor reveals that just a third (34%) of people think it's possible to reduce their risk of developing dementia.

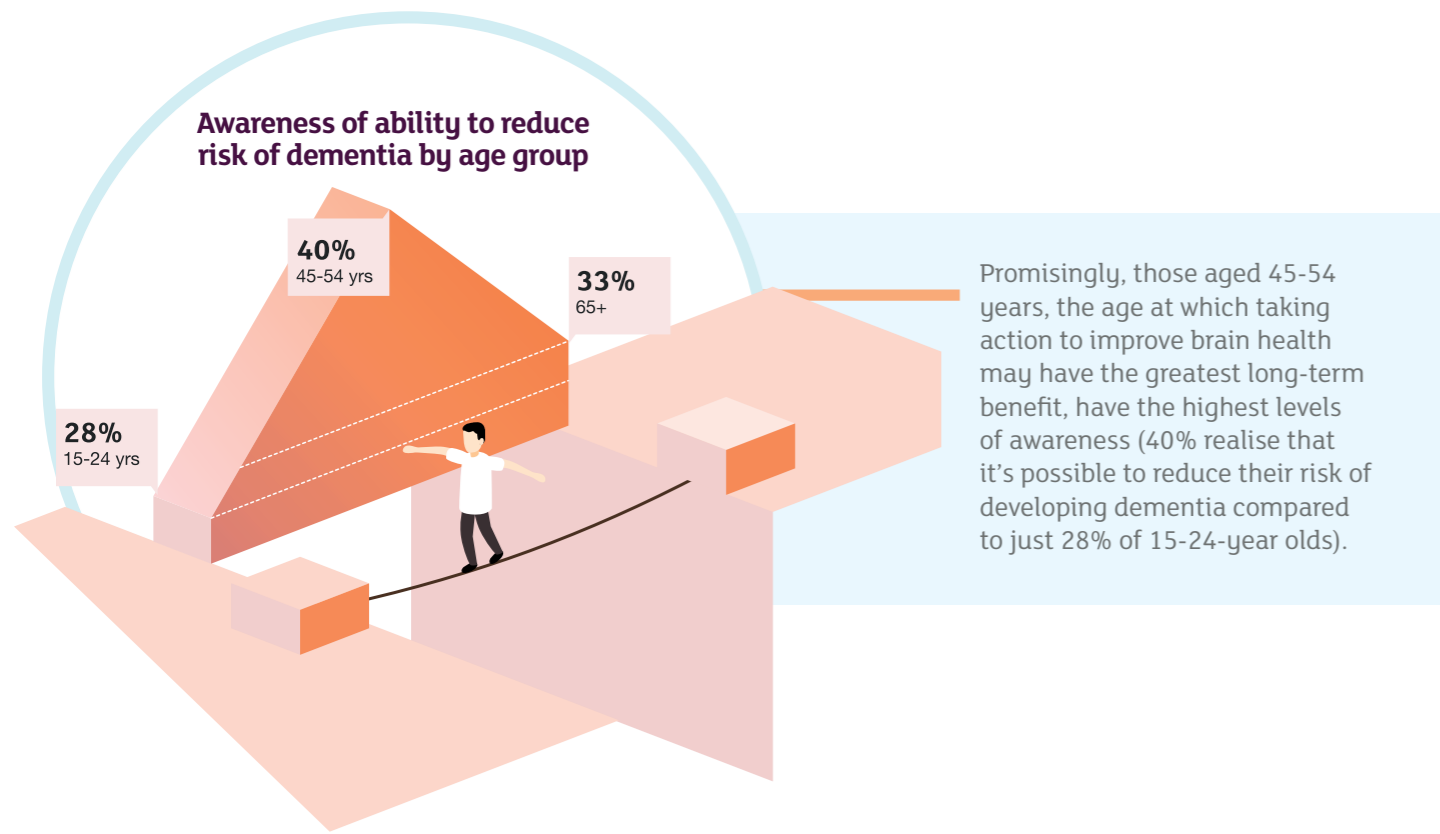
Although this figure is slightly higher than similar Alzheimer's Research UK polls in previous years, awareness is still disproportionately low compared to other health conditions, highlighting a clear need for continued and expanded public health messaging around dementia risk.



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



Awareness of ability to reduce risk of dementia by age group



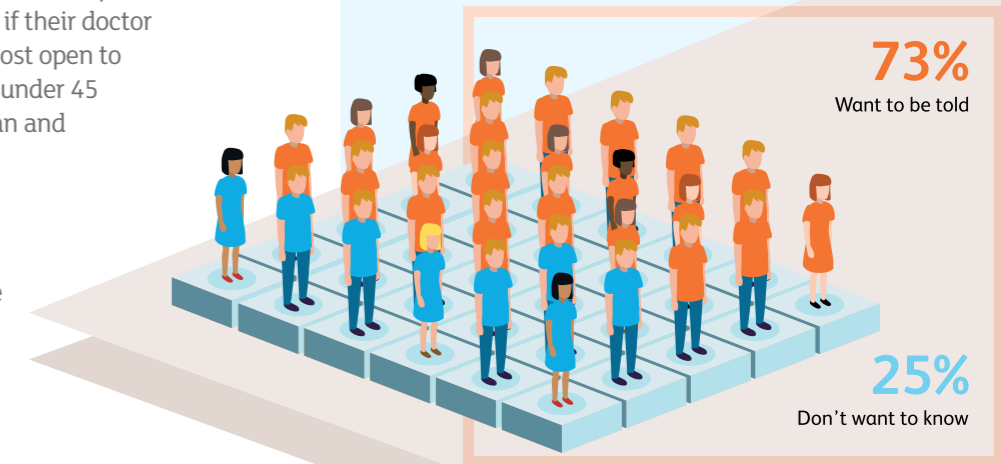
Promisingly, those aged 45-54 years, the age at which taking action to improve brain health may have the greatest long-term benefit, have the highest levels of awareness (40% realise that it's possible to reduce their risk of developing dementia compared to just 28% of 15-24-year olds).

A strong desire for information on dementia risk

Despite a lack of awareness, the Monitor reveals a strong desire among the UK public to be given information about their own personal dementia risk. The majority of UK adults (73%) say they would want to be told in midlife about their personal risk of developing dementia later in life, if their doctor could provide this information. Those most open to being told their risk in midlife are those under 45 years (77%) and people from black, Asian and minority ethnic backgrounds (77%).

Those less likely to want to know their risk included over 65s (32%), those with no formal qualifications (35%) and those who held the opinion that there is no value in being given a formal diagnosis of dementia (58%).

'Would want to know their risk of developing dementia'



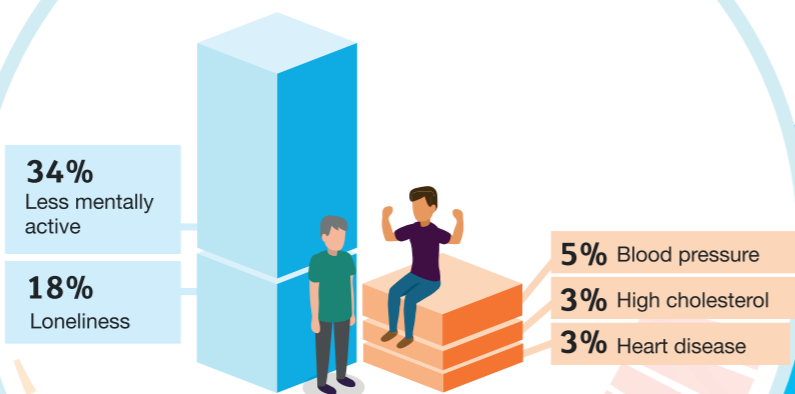
Low recognition of physical risk factors for dementia

When asked, the public are more likely to name non-physical risk factors for dementia such as being less mentally active (suggested by 34% of people) and loneliness (18%) than risk factors like high blood pressure (5%), high cholesterol (3%) and heart disease (3%). This is despite research to support physical risk factors for dementia currently having the strongest evidence base.

In 2015, the British Social Attitudes survey found that only 1% of UK adults could correctly identify seven risk or protective factors for dementia (risk factors: heavy drinking, genetics, smoking, high blood pressure, depression and diabetes, protective factor: physical exercise), while 22% of the UK public failed to identify any at all. When this question was repeated as part of the Dementia Attitudes Monitor, again just 1% of the public correctly identify all seven factors, while approaching half (48%) fail to identify any.

Although not directly comparable, the findings from these surveys suggest that despite an increase in general awareness of dementia risk, the public's understanding of what those risk factors are is not improving at the same pace. Showing the public how to maintain good brain health and reduce their risk of developing dementia, including through the amplification of 'what's good for your heart is good for your head' messaging, remains crucial.

Awareness of dementia risk factors



Taking action

Over the past two years, we've worked alongside Public Health England and Alzheimer's Society to make dementia risk reduction information mandatory in NHS Health Checks for people aged 40-64 years. The Dementia Attitudes Monitor shows a clear need to continue to expand public health messaging campaigns around brain health and dementia.

In 'No time to lose', Alzheimer's Research UK's action plan for dementia published last year, we called on the UK government to spearhead dedicated dementia risk reduction and wider brain health campaigns for the public and medical professionals. Any organisation or individual whose activities have the potential to influence the health behaviour of others must take into account the importance of sharing positive brain health messaging with others, whatever their stage in life.

Wave 1 of the Dementia Attitudes Monitor shows clear public support for information about dementia risk. With research moving towards risk profiling as a way to identify those most likely to benefit from future treatments, these findings will provide an important basis for ongoing discussions about how the NHS prepares for the delivery of such breakthroughs.



Diagnosis and treatment

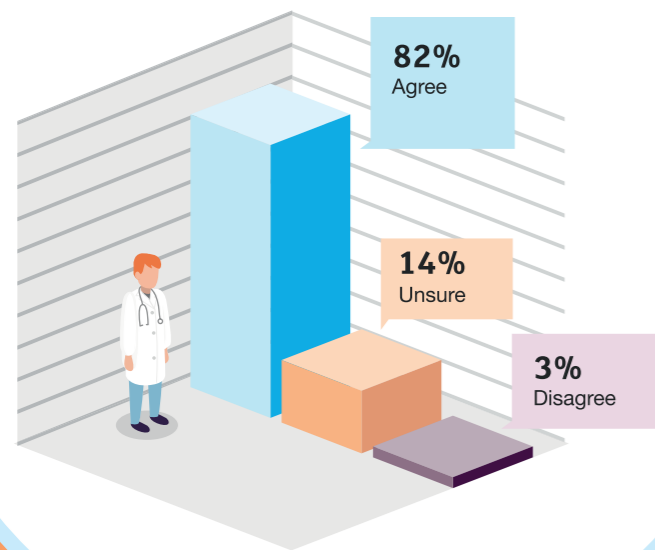
Five years ago, less than half of people with dementia in England received a formal diagnosis of their condition. Following a government-led drive to improve diagnosis rates, 67% of people with dementia in England had been formally diagnosed in 2018.

The public sees value in a formal dementia diagnosis

The Dementia Attitudes Monitor reveals widespread support for people with dementia being given a formal diagnosis from a doctor - 82% agree that there is value in being given a formal diagnosis from a doctor, compared with just three percent who disagree.

The most common reasons given for seeing a value in a formal diagnosis were to allow people to 'plan for their future' (59%), 'access treatments that could help' (50%) or 'access care that could help' (47%). Of those who did not see value in a diagnosis, the most common reason was that it was 'too stressful for the person being diagnosed' (43%).

'There is value in being given a formal diagnosis'

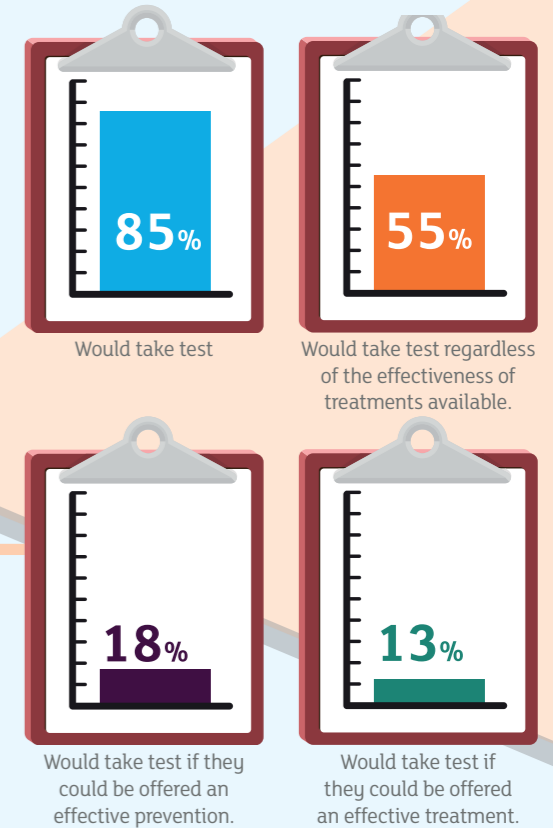


Openness to advances in the pre-symptomatic detection of disease

With breakthroughs in treatment development likely to rely on people being diagnosed much earlier in their disease, even before symptoms show, we explored public attitudes towards very early detection and diagnosis of diseases like Alzheimer's. The Monitor reveals widespread public support, with the vast majority of people (85%) saying they would take a test, or set of tests, that could tell whether they were in the very early stages of Alzheimer's disease or another form of dementia, even before the symptoms showed.

Just over half (55%) would take the test regardless of the effectiveness of treatments available. One in five people (18%) said they would only take the test if they could be offered an effective prevention and one in eight (13%) would do so if they could be offered effective treatment.

'Would take a test that could tell if they were in the early stages of a disease like Alzheimer's'





Greater support for less invasive diagnostic tests

We explored the public's openness to particular types of test that could help a doctor to diagnose a disease like Alzheimer's in future. The vast majority of the UK public would be willing to undergo less invasive tests such as an eye test, a blood test and a memory/thinking test (for each of these tests, 91% would be willing to take them), while 87% would be willing to have a brain scan and three quarters (73%) would agree to using computer/smartphone tasks that monitor day-to-day life. Fewer people (44%) are willing to undergo a lumbar puncture to make an accurate and early diagnosis, with a greater proportion being reluctant undergo such a procedure (54%).

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

Misunderstanding around current dementia treatments

The availability of an effective treatment is a driver of whether people would be willing to undergo tests to detect diseases like Alzheimer's at an early stage. Overall, 50% of people say that current dementia treatments are not effective, just a quarter (27%) consider them to be effective and one in five people (22%) is unsure either way.

However, when we asked people to identify the types of treatments currently available for dementia from a list of eight, there were clear pockets of misunderstanding. Although people were most likely to correctly identify interventions such as group therapy to stimulate memory and thinking skills (44%), as well as medicines to help relieve symptoms (36%), 31% incorrectly agreed there were 'medicines available on NHS prescription to slow the underlying diseases like Alzheimer's that cause dementia'. A smaller number also believed there were medicines available on NHS prescription to 'stop the underlying diseases that cause dementia' (15%) or even 'prevent dementia developing in the first place' (12%).

Effectiveness of current treatments



Taking action

With research showing that identifying those in the early stages of a disease like Alzheimer's will be essential for the development and delivery of future treatments, the results from the Monitor highlight a very receptive audience to such advances. This sets the groundwork for future policy developments that will ensure the NHS is ready for the delivery of new treatments for dementia as well as developments in risk profiling.

The perceived effectiveness and availability of current treatments is an important driver of public openness to advances in diagnostic technology. For that reason, we must continue to be clear about the treatment options currently available, while helping people to understand the value of early detection and diagnosis for enabling future treatment breakthroughs.

This message is particularly relevant for the over 55s for whom such advances are most likely to be of immediate benefit, but who are less likely to see a value in a formal diagnosis, be open to pre-symptomatic diagnostic tests or be willing to use emerging digital technologies to aid the detection and diagnosis of diseases like Alzheimer's.

Case study



“ 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 that 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



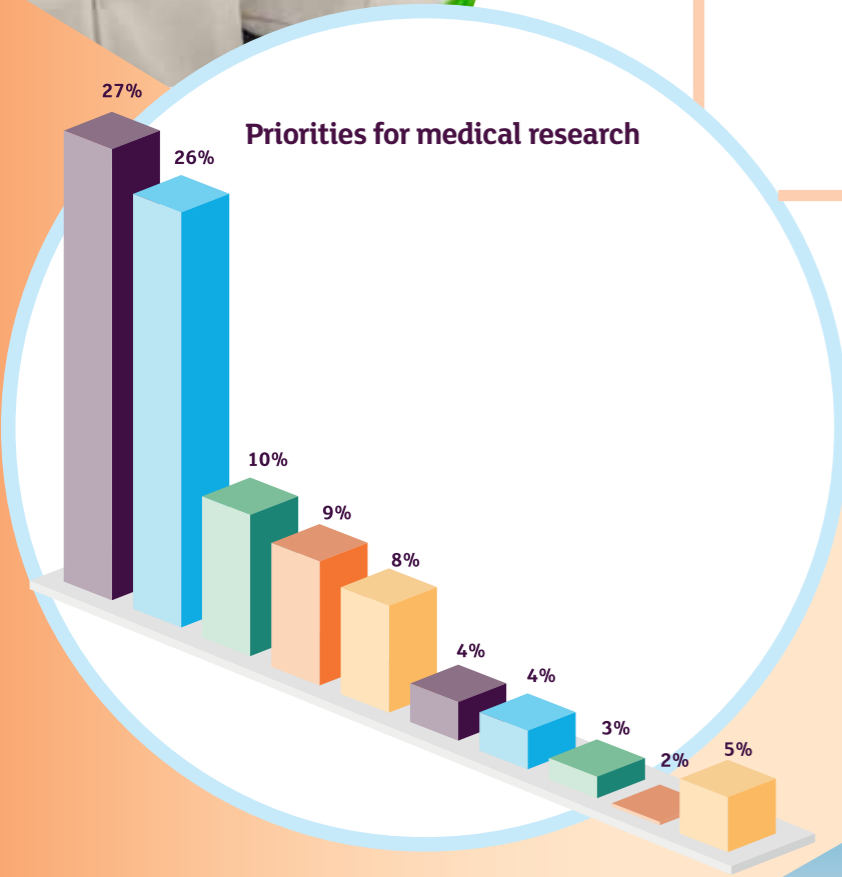
Research

Cure and prevention named as top research priorities

The public's key priorities for medical research are work towards finding a cure (27%) and ways to prevent the diseases that cause dementia (26%). These areas are prioritised more highly than research into ways to improve the quality of life through better care (8%) or research into drug (4%) or non-drug (3%) treatments to help with symptoms.

While all are important avenues of research and have the potential to make a significant impact on the lives of those living with dementia and their families, the data send a strong signal to research funders that the public wants researchers to be bold in their ambitions and supports efforts to transform how dementia is prevented and treated in future.

- Research for a cure (27%)**
- Research for ways to prevent the disease (26%)**
- Research for new forms of medication to stop the disease (10%)**
- Research for ways to diagnose the disease earlier (9%)**
- Research for ways to improve quality of life through better care (8%)**
- Research for new forms of medication to slow the disease (4%)**
- Research for new forms of medication to help with symptoms (4%)**
- Research for non-drug treatments and therapies to help manage symptoms (3%)**
- None of these (2%)**
- Don't know (5%)**



Opportunity to encourage greater public involvement in research

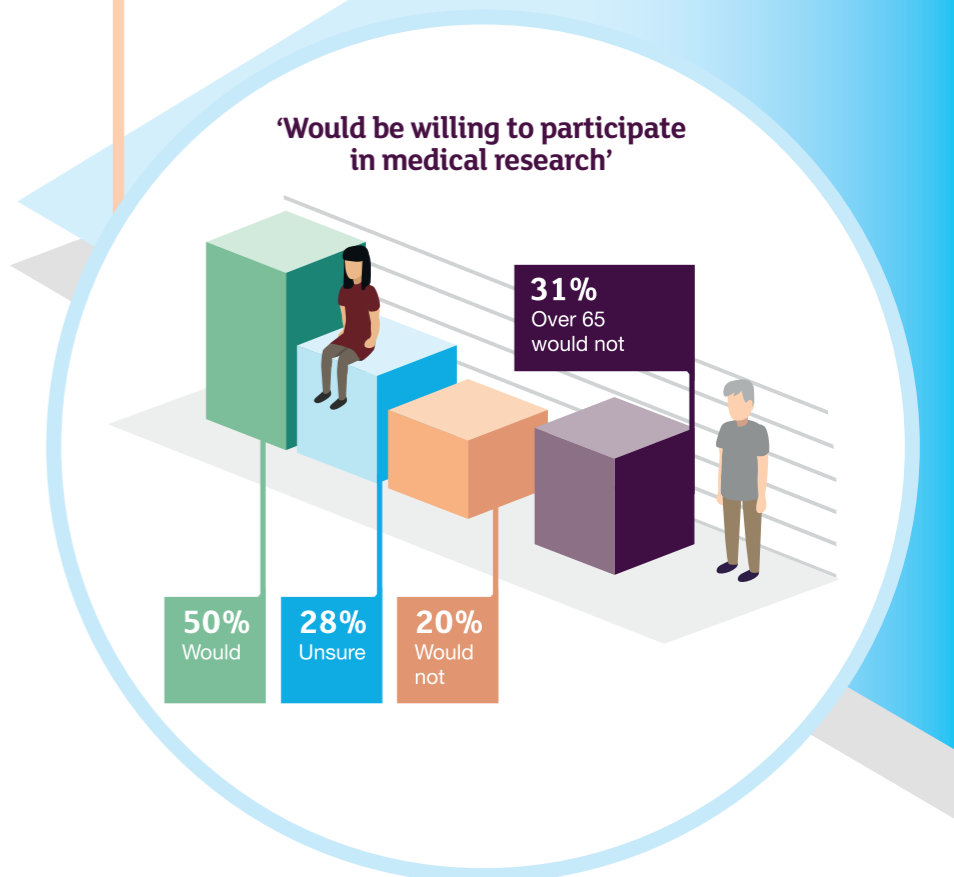
The Dementia Attitudes Monitor shows a clear opportunity to engage the public with their own personal role in research and the difference their involvement could make. Half of those surveyed, would, hypothetically, be willing to get involved in medical research for dementia in the future; 20% would not and a further 28% are unsure.

By age, those over 65 are least likely to consider getting involved in medical research for dementia, with 31% not willing to get involved compared with 20% overall. Similar variations were found by education level, with 31% of people with no formal qualifications saying they would not be willing to get involved 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%).

In October 2018, we followed up the findings in an independent Ipsos MORI poll of 2,011 UK adults to explore the reasoning behind people's response. For those aged 55 and above, perhaps the most important age group for research involvement, the main reasons given for someone's willingness to get involved in research were '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 reasons given by those aged 55 and above who would not be willing to get involved in research are that 'I don't know enough about what it would involve' and 'I don't have enough time'.



Taking action

The strong public support for ambitious research objectives such as delivering preventions and cures gives a strong mandate to dementia research funders to match the scale of ambition in the development of their own funding strategies. Alzheimer's Research UK has pledged to commit a further £250m to dementia research before 2025 and we're calling on government to invest 1% of the annual cost of dementia to the UK economy in research by this date to speed up the search for life-changing preventions and treatments.

In addition to funding research, charities, government and the NHS must work hard to engage people with the personal role they can play in making such breakthroughs possible. Initiatives like Join Dementia Research, launched in 2015, have already seen over 38,000 people register their interest in volunteering for research. The results from the Monitor show a clear opportunity for further engagement, particularly with over 65s, who show the greatest reluctance to contribute directly to research studies.

Better understanding of motivations and the barriers people face in volunteering for medical research into dementia is vital for developing campaigns to address these, for example improving education about what getting involved in research means and the many types of studies a person can volunteer for.

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.

Find out more

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



Full Dementia Attitudes Monitor Report

Please read the full Wave 1 Dementia Attitudes Monitor Report for a comprehensive analysis of UK attitudes towards dementia and research.

www.dementiastatistics.org/attitudes



No time to lose: An action plan for dementia

Alzheimer's Research UK is committed to increasing our investment in dementia research every year so we can one day achieve a world free from the fear, harm and heartbreak of dementia. We need government to do the same.

Read our action plan for details about how government, along with industry and charities, can help bring about the first life-changing treatment for dementia by 2025.

www.alzheimersresearchuk.org/actionplan



An introduction to dementia

Short on time or just need an introduction to dementia? Our 'Quick guide to dementia', available below in English and seven other languages, provides the basic facts about dementia in simple terms.

www.alzheimersresearchuk.org/quick-guides

Looking to the future

The overall aim of the Dementia Attitudes Monitor is to act as a catalyst for wider public dialogue around dementia, informing ongoing charity and government efforts to overcome the condition.

Following Wave 1, 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 efforts in dementia research.

By tracking public attitudes to dementia and research over time, we hope to gain detailed insight that will help to ensure future communications and campaigns reach the right audiences with the right messages to change lives.



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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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.

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.

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.



**Alzheimer's
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