

Detecting and diagnosing Alzheimer's disease

Enhancing our understanding of public attitudes
to improving early detection and diagnosis

December 2019



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1. Foreword

Dementia is one of the biggest challenges of our time. Over 850,000 people in the UK are living with the condition and more than half of us will know someone affected by it.ⁱ Dementia is now the leading cause of death in the UK and there are no effective treatments to slow, stop or prevent the diseases, like Alzheimer's, that cause it – yet.

The growing investment in dementia research is beginning to reap rewards and there are an increasing number of clinical trials for dementia underway. Considerable progress is also being made with new detection and diagnostic methods.

The arrival of new treatments will fundamentally change the way society thinks about dementia. In particular it is likely that new treatments will need to be offered at a much earlier stage, possibly before we observe clinical symptoms. Making the decision to undergo treatment at this stage will require wider conversations about risk and our understanding of disease progression with potential patients.

We also know that public understanding of dementia has historically been poor, despite increasing awareness of the condition. The challenge of explaining a complex medical condition, together with the fear and helplessness typically associated with developing dementia, has meant that many people would prefer not to engage with the topic. How do we engage the public in conversations about detecting the earliest changes in the brain that could lead to dementia?

This report aims to provide insight into how to address these issues. What does the public understand currently, and what are their fears and concerns? Insight is, of course, only the start of the process, and the next steps to address these issues will be crucial.

Prof Jonathan Schott

Alzheimer's Research UK Chief Medical Officer



2. Executive summary

Dementia is the UK's leading cause of mortality, overtaking heart disease in 2017.ⁱⁱ Over 850,000 people are currently living with dementia, of which Alzheimer's disease is the most common cause, affecting six in every 10 people with dementia.ⁱⁱⁱ Currently, there are no treatments that will slow or prevent the onset and progression of Alzheimer's disease.

However, every day we are learning more about the changes in the brain that lead to dementia and clinical trials are ongoing across the world into new potential therapies to treat the diseases that cause it. There is also research underway into the risk factors associated with Alzheimer's and other diseases that cause dementia. As research advances our understanding of these diseases, it has become increasingly clear that early detection and diagnosis are of the utmost importance. Focusing efforts here both ensures that people are given the opportunity to plan for the future and live as well as possible with their condition, while enabling them to contribute to rapidly-developing research into new treatments.

A diagnosis of any form of dementia – or even detection of the early changes in the brain that could lead to its development – can be frightening, so it is important that the NHS is prepared to support and reassure people throughout their care pathway. This means ensuring people can receive an early diagnosis, helping them to understand what to expect from the condition, and supporting them, their carers and their loved ones to live as well as they can.

To support the NHS and the dementia community to deliver progress in research and care that the public, people with dementia and their carers want, MSD and Alzheimer's Research UK commissioned Populus to undertake research into public

understanding of the detection and diagnosis of Alzheimer's disease. We chose to focus on Alzheimer's disease for this research because, as the most common cause of dementia, research into the disease is advancing at pace.

We held a series of focus groups, followed by a public survey, to gain insights into the breadth and depth of public attitudes towards this area of work. As part of this research, we explored:

- Attitudes towards the detection and diagnosis of Alzheimer's disease, including what it might mean to be found to be at elevated risk, and to have a diagnosis before symptoms have started.
- Attitudes towards the different types of tests for detecting and diagnosing Alzheimer's disease, including those currently available and those currently in development.
- The implications, if a new treatment were to become available, of people's attitudes towards pre-symptomatic detection and testing.

By exploring these issues, we can understand more about how the NHS and wider dementia community must now work together to implement developments in improved detection and diagnosis to achieve the best possible experiences for people living with the disease now and in the future.

Headline findings from our research revealed:

20%

of people wrongly believed that Alzheimer's disease and dementia are the same thing

While most people were aware of Alzheimer's disease, there remains considerable confusion about the disease. **20% of people wrongly believed that Alzheimer's disease and dementia are the same thing**; this increased to 32% for current or former carers for someone living with dementia.

49%

of people believed Alzheimer's begins decades before any symptoms emerge

Over half of UK adults don't know that Alzheimer's disease starts decades before symptoms of dementia, such as memory problems, show. **49% of people believed, as current evidence suggests, that Alzheimer's disease begins decades before any symptoms emerge**; this increased to 60% for current or former carers for someone living with dementia.

74%

of people would want to know if they had Alzheimer's before symptoms develop

There is significant interest in finding out whether someone will develop Alzheimer's disease, although the public requires accuracy of results and certainty of disease progression. **74% of people would want to know if they, or a family member, had Alzheimer's disease before symptoms develop.**

75%

of people were willing to undertake most forms of testing

At least 75% of people agreed that they would be willing to undertake cognitive tests, brain imaging, blood tests and eye tests to help identify their risk of developing the disease. This dropped to 40% who were willing to undertake cerebrospinal fluid sampling.

67%

of people agree that diagnosing people with Alzheimer's disease still matters

67% of people agree that diagnosing people with Alzheimer's disease still matters, even if we can't help them. This rose to 80% for people who are or were carers for someone with dementia.

Within this report, we make a number of recommendations for action that should be taken by policymakers in conjunction with the dementia community to improve early detection, diagnosis and support for people undergoing tests for or living with Alzheimer's disease.

Improving communication with patients and the public

1

The NHS should make available **clear, accessible information on Alzheimer's disease and dementia**, including the differences between the two and the development of the disease from pre-symptomatic stage, through a range of communication channels.

2

The NHS should work with the dementia community to develop **guidance to support healthcare professionals' discussions about Alzheimer's disease and dementia** with patients and their carers and family. This should include guidance on appropriate language to use when discussing detection and diagnosis.

3

The NHS should work with patient groups and charities to develop **more accessible information for the public on how Alzheimer's disease is currently diagnosed**, including information about the most effective and accurate tests, and the benefits of early diagnosis.

Supporting earlier detection and diagnosis

4

The research and health communities, in conjunction with patient and public representatives should agree **a common and consistent language to describe detection and diagnosis of Alzheimer's disease**. These communities should also work together to establish a greater understanding of the stage at which diagnoses are currently being made, for example through an agreed definition of the language, stages of progression and methods of analysis.

5

The NHS should **include conversations about risk factors and wider brain health as standard during any appropriate interaction**, including routine NHS and non-NHS health checks.

6

The NHS should **pilot a risk-stratified approach towards diagnosis**, with the aim of increased use of appropriate diagnostics (such as CSF or blood tests in due course) earlier in the disease progression.

7

The NHS and dementia community should work together to develop an action plan of **communications and engagement activities and opportunities to improve public understanding of CSF** and its role in detecting Alzheimer's disease.

8

The dementia community should seek to **better understand current clinical perceptions towards the tests used to detect and diagnose Alzheimer's disease** and the key role they play in patient attitudes.

Preparing the NHS for future treatments

9

The Department of Health and Social Care should undertake work to **prepare the healthcare sector to be able to detect the diseases that cause dementia 10-15 years before symptoms appear**. This includes horizon scanning of diagnostic techniques that could be used at scale.

10

The Department of Health and Social Care should undertake modelling into what **changes are needed in the diagnostic pathway to support access to both current symptomatic treatments and future treatments** – whether symptomatic or disease-modifying. For example, this could include piloting brain health clinics as a new service model for detection and earlier diagnosis of Alzheimer's.



3. Introduction

Every three minutes someone in the UK develops dementia.^{iv} Despite this, there are currently no treatments that can slow, stop or prevent the diseases, like Alzheimer's, that cause the condition. Unless we find life-changing preventions and treatments, one in three people born today will develop dementia in their lifetime.^v

We are making progress towards better understanding of the diseases that cause dementia. Clinical trials are ongoing across the world, but there is still much more we need to learn about dementia and how we can prevent or treat it in the years ahead.

Research efforts are focused on pathological changes in the brain that occur before the onset of symptoms, when potential treatments are likely to be more effective. As such, the need for early detection and diagnosis of the diseases that cause dementia is becoming more acute. Diagnosis rates of dementia in the UK have improved markedly in recent years, but there is still scope both to improve diagnosis rates and ensure that the diseases that cause dementia are detected as soon as possible.

A diagnosis of dementia can be frightening, but it is crucial so that people living with dementia – and the people who love and care for them – can access the support and information they need. Understanding public attitudes towards the early detection and diagnosis of Alzheimer's disease and other dementias is vital to help the NHS ensure people are given the opportunity to plan for the future, enable them to contribute to rapidly-developing research into new treatments, and, ultimately, access these new treatments once they become available.

While a number of studies, including Alzheimer's Research UK's Dementia Attitudes Monitor,^{vi} have illuminated different aspects of public attitudes to dementia – from concerns about stigma to the importance of high-quality post-diagnostic support – there is still more we need to know.

This report showcases the findings of in-depth analysis undertaken by Populus for Alzheimer's Research UK and MSD on public attitudes towards the detection and diagnosis of Alzheimer's disease, and dementia more broadly. It examines views on:

- Terminology surrounding risk monitoring, detection and diagnosis of dementia.
- Attitudes towards the risk of developing Alzheimer's disease and dementia.
- Attitudes towards different types of diagnostic tests for Alzheimer's disease and dementia.
- How the development of new ways of treating Alzheimer's disease and dementia might affect attitudes towards detection and diagnosis.

The aim of this piece of research is to gain more insight into each of these areas. It builds on and contributes to existing work being undertaken by Alzheimer's Research UK and the Dementia Access Taskforce, a coalition of organisations, led by Alzheimer's Research UK, working together to prepare the NHS, the clinical community and the public for future treatments for dementia.

This report includes a number of recommendations for action that should be taken by policymakers to ensure the infrastructure is in place to support earlier detection and diagnosis of Alzheimer's disease, and to improve public understanding of the disease. It is aimed primarily at a policy audience; however, there are key learnings that can be taken on board by the clinical and carer communities to inform the care and support they provide for people at risk of or living with Alzheimer's disease.

While the report focused on the early detection of Alzheimer's disease more specifically, we recognise there are many other causes of dementia. We hope that these results will start conversations relevant to the improvement of detection and diagnosis of all forms of dementia. We also know that there are particular challenges with the detection and diagnosis of young-onset dementia, with an estimated 40,000 people (~5% of the dementia population) living with young-onset dementia.^{vii} We hope that the insight of this report will be relevant and pertinent to helping address those issues. Alzheimer's Research UK and MSD are both committed to working with stakeholders across government, Whitehall and the dementia community to implement these recommendations.

Methodology

Alzheimer's Research UK and MSD commissioned Populus to undertake the research for this report. We decided to focus primarily on Alzheimer's disease, although some questions touch on dementia more broadly to better understand public awareness of the relationship between the two. Moreover, Alzheimer's disease is the most common cause of dementia, and research into the disease is advancing at pace.

When commissioning the research, we set the following objectives:

1. Develop deeper understanding of and insight into public perceptions and attitudes to the early detection and diagnosis of Alzheimer's disease and dementia through both qualitative and quantitative research.
2. Identify any publicly perceived challenges, barriers or unintended consequences in offering early detection and diagnosis.
3. Strengthen the evidence base around early detection and diagnosis of Alzheimer's disease and potential approaches to monitoring those at risk of developing the disease.

The research was undertaken in two phases:

Focus groups: a series of five focus groups were held in London, Manchester and Birmingham. There were six participants in each 1.5-hour focus group, drawn from members of the public aged 20-65, with an equal split of gender, spread of social grade A-C2 and age range. Four of the focus groups had participants with limited prior experience of dementia and one focus group had participants with direct experience (i.e. partner or family friend). All fieldwork was completed between 5 and 7 February 2019.

The aim of this phase was to gain a deeper understanding of people's reactions and emotions when discussing the detection and diagnosis of dementia and Alzheimer's disease. The findings from these initial focus groups were fed through into the next phase of the research.

Polling: a survey of 2,106 UK adults (18+) was undertaken between 4 and 5 March 2019. Respondents were drawn from people who have a friend or family member with dementia (967), people who are or were carers for someone with dementia (123) and people with no personal connection to dementia (1,051). We split respondents into two equal cohorts so as to test attitudes – and how they might differ – in the following scenarios:

1. Currently there are no available treatments that slow the progression or delay the onset of Alzheimer's disease. The treatments that are available can help ease the symptoms of Alzheimer's disease once they emerge, but not the underlying causes, which may begin up to 20 years before.
2. There are a number of potential treatments in development that could slow or delay the progression of Alzheimer's disease. For the following questions please imagine that such a treatment was available to anyone who needed it (whether or not they have symptoms such as memory loss).

This allowed us to understand how the system might need to change to prepare for potential future treatments. This research phase gave us breadth of insight into public attitudes, where the focus groups had provided depth.

4. Public understanding of Alzheimer's disease

In order to form a baseline from which to understand public perceptions of detecting and diagnosing Alzheimer's disease, our research first explored public understanding of Alzheimer's disease and dementia, including the differences between the two terms. Whilst many people have heard of – or are indeed directly impacted by – dementia, the complexity of the diseases that cause dementia mean there are often misconceptions about the condition, its symptoms and how it differs from normal ageing.

What is dementia?

Dementia is not a disease in itself. Dementia is an umbrella term used to describe the symptoms that are associated with a group of brain diseases. When brain cells stop working properly, symptoms occur depending on which specific area of the brain has been affected. Symptoms include memory loss, confusion, mood changes and communication difficulties.

The diseases that cause dementia are classified according to which areas of the brain are affected and how. These include Alzheimer's dementia, vascular dementia, dementia with Lewy bodies, frontotemporal dementia and Parkinson's dementia.

Currently over 850,000 people in the UK are affected by dementia.

What is Alzheimer's disease?

Alzheimer's disease is the most common disease that causes dementia, affecting around 500,000 people in the UK.

Alzheimer's disease causes changes in the brain including the accumulation of two proteins, called amyloid and tau. As the disease progresses, more and more brain cells are damaged. This damage leads to the symptoms of dementia, which are currently irreversible.

The majority of people who develop the disease are over the age of 65. Although Alzheimer's disease becomes more common with age, it is not a normal part of ageing.

Research is ongoing to understand more about how Alzheimer's disease damages the brain and to find new ways to treat the disease.

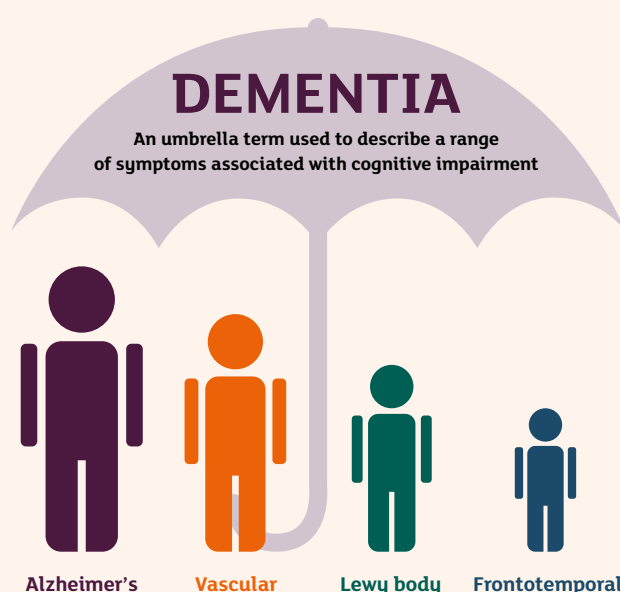
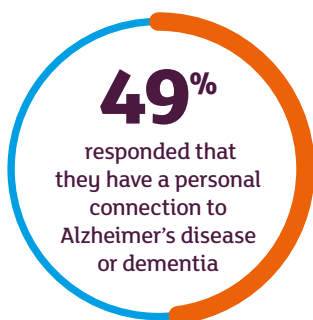


Figure 1: Different types of dementia



As part of our polling, we asked about respondents' connection to Alzheimer's disease: **49% responded that they have a personal connection to Alzheimer's disease or dementia**, similar to that seen in Wave 1 of the Dementia Attitudes Monitor. Alzheimer's disease is most commonly described by the public as memory loss that comes with ageing or a disease of the brain.

The focus groups explored this connection as well, taking a closer look at the way people reacted when talking about Alzheimer's disease – and the challenges that these reactions create for promoting understanding of the disease with the public. Researchers guiding the discussion reported a common theme of **disengagement** with the topic across all of the focus groups: people were not comfortable discussing Alzheimer's disease. Negative **body language** was clear, such as crossing arms, moving away, not wanting to make eye contact. Participants used emotive language – “devastating”, “trauma”, “scary” were commonly used terms (see Figure 2 immediately below). This was particularly clear among those who have **experience of Alzheimer's disease**, having seen first hand its effect on friends and family.

Worrying
Death
Elderly Sad
Incurable
Memory
Terrible Lonely Scary
Degenerative
Trauma
Devastating

Figure 2: Emotive language used during focus groups

A cycle of disengagement when discussing Alzheimer's disease over the course of the focus groups can be broken down into four stages:

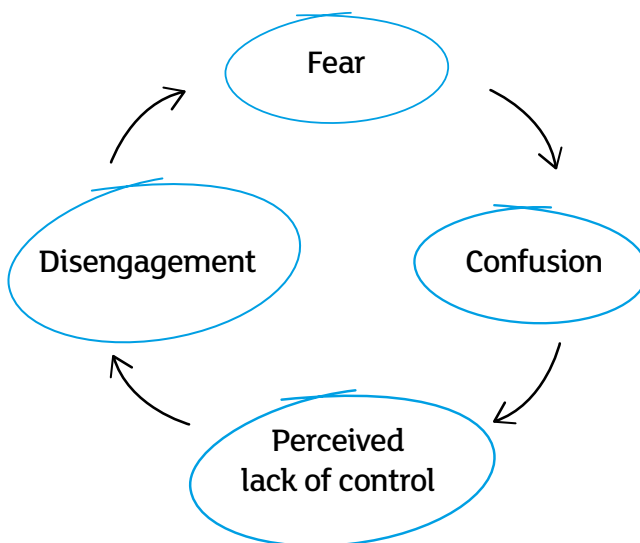


Figure 3: Cycle of disengagement

“It’s a death sentence. You can be physically fit but can’t even make a cup of tea or recognise anyone. It’s a long, sad process.”
(Source: Populus 2019)

Each of these stages pose barriers to public understanding of the disease – a significant challenge facing the Alzheimer's disease community when raising awareness, understanding and knowledge of the disease. This framework helps to set the scene for the subsequent chapters of this report, which explore public attitudes towards the detection, diagnosis and potential treatment of Alzheimer's disease.

“You wouldn’t wish to have it or wish it on anybody. It’s something I dread because there is no cure. I have relatives that have had it and you just go into denial.”
(Source: Populus 2019)

We asked people whether they agreed with the statement *Alzheimer's disease and dementia are the same thing*. 20% of respondents agreed (Figure 4). This increased to 32% for those who are a carer for someone living with Alzheimer's disease or another form of dementia. However, the number of people who answered "don't know" decreased

significantly from 31% among people without a personal connection to dementia to 6% for those who are or have been carers, and disagreement with the statement rose from 53% to 62%. There was also variation between men and women, with 52% of men disagreeing with this statement, compared to 62% of women.

Alzheimer's disease and dementia are the same thing

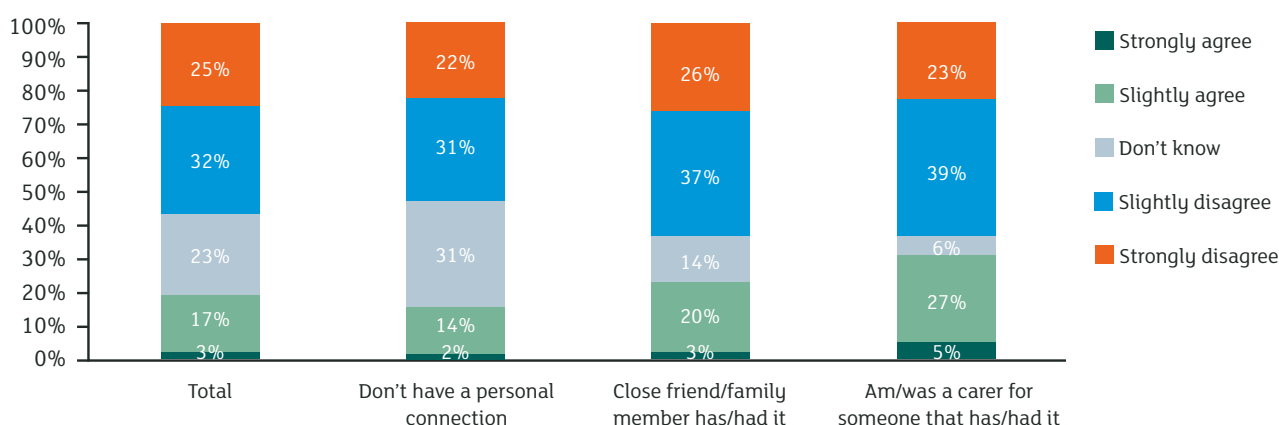


Figure 4: Early diagnosis of dementia survey, Populus (2019)

Alzheimer's stages

Alzheimer's is a progressive disease, although the rate at which the disease progresses varies. Eventually, the disease will damage most areas of the brain. Memory, thinking, judgement, language, problem-solving, personality and movement can all be affected by the disease, and these symptoms gradually worsen over time.

The normal course of Alzheimer's disease is divided into five increasingly severe stages, during which the terminology we use transitions from pre-symptomatic Alzheimer's disease through to Alzheimer's dementia:

1. Pre-symptomatic Alzheimer's disease

Changes in the brain caused by Alzheimer's disease begin years before any symptoms appear. This is called the pre-symptomatic stage of Alzheimer's disease, and is currently only identified in research settings. People in this stage have biological markers of the disease, such as the accumulation of amyloid in the brain, but show no symptoms. This stage can last up to two decades.

2. Prodromal Alzheimer's disease

People in this stage are characterised by having biological markers of the disease, as above, as well as mild cognitive impairment (MCI). People with MCI show mild cognitive symptoms, as their memory and thinking ability is mildly impaired. These symptoms are not severe enough to be classed as dementia.

Although people with MCI have an increased risk of developing dementia, not all develop the condition. Currently, monitoring and further investigation can help determine whether MCI is due to Alzheimer's disease or another cause.

3. Mild Alzheimer's dementia

This stage is often when Alzheimer's disease is diagnosed, as symptoms become more obvious. People in this stage are still able to function independently, but start showing problems in memory or concentration that have an impact on day-to-day life. Performance on memory and thinking tests are affected and doctors will be able to detect impaired cognitive function.

4. Moderate Alzheimer's dementia

During the moderate dementia stage of Alzheimer's, people grow more confused and forgetful and begin to need more help. Damage to nerve cells in the brain can make it difficult to express thoughts and perform routine tasks.

5. Severe Alzheimer's dementia

In the late stage of the disease, mental function continues to decline, and the disease has a growing impact on movement and physical capabilities. In this stage, the person eventually becomes unable to communicate verbally and requires complete assistance with personal care and all daily activities.

Not all people experience the stages of Alzheimer's disease in the same way, and the rate and extent of the progression is varied and dependent on the individual.

A person may not show all the symptoms that are characteristic of a stage, and specific symptoms may appear temporarily and then disappear. The boundaries of these disease stages can also be blurred.

Current scientific evidence suggests that disease-modifying treatments for Alzheimer's disease will be most effective when started in the earlier stages of the disease, ideally before symptoms start – in the pre-symptomatic stage.

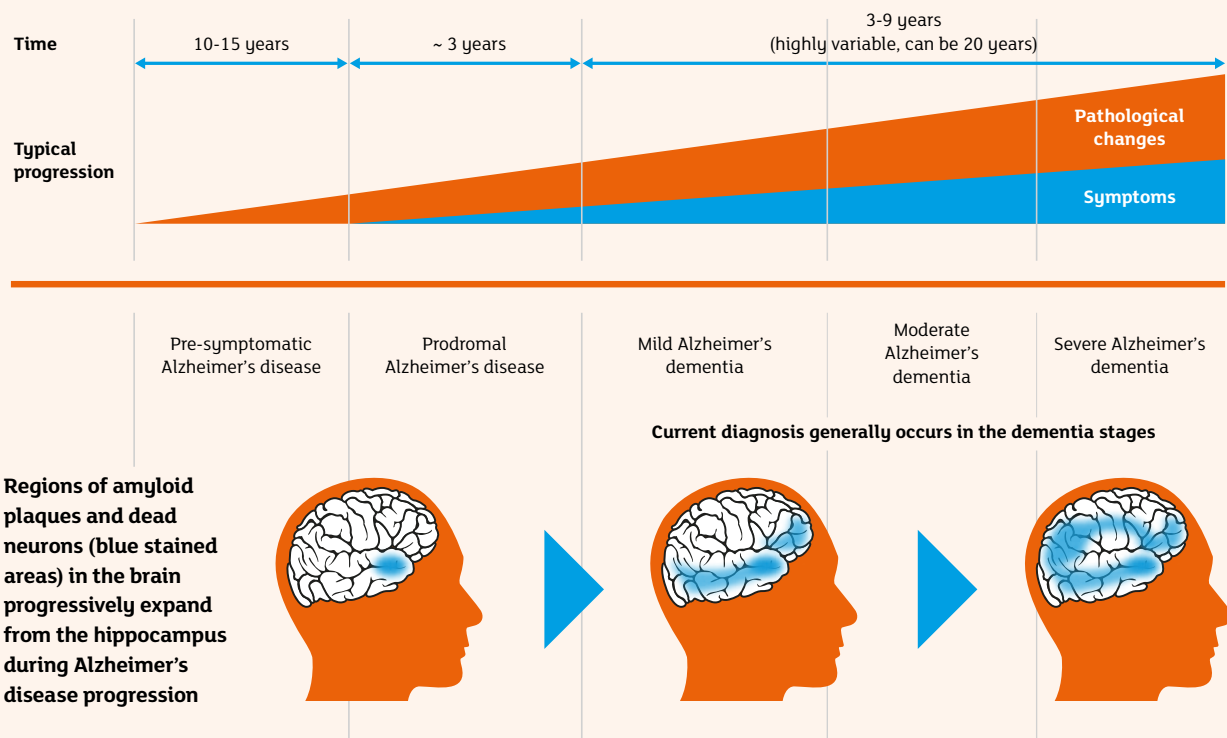


Figure 5: The stages of Alzheimer's disease

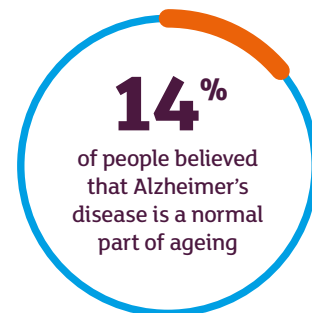
While over half of people surveyed recognised there is a difference between Alzheimer's disease and dementia, there was still a lack of understanding of the relationship between the two. Interestingly, this rose with greater exposure to dementia, which contradicts some of the findings later in this report that reveal a stronger understanding of Alzheimer's disease among this group. While this finding is also at odds with the findings from the Dementia Attitudes Monitor Wave 1 Report, it may indicate that the information they receive is either confusing or irrelevant to the lived experiences they are going through as family, friends or carers.

The results of the focus group discussions were supportive of this hypothesis, with participants feeding back that information about Alzheimer's disease or dementia can be confusing. This in turn fuels the cycle of disengagement set out in the previous chapter, creating barriers to public understanding of the disease.

Perceptions of Alzheimer's disease as a part of the ageing process

Around 3/4 of those surveyed disagreed with the statement that *Alzheimer's disease is a normal part of ageing*; however, there remained a significant proportion (14%) of people who agreed that Alzheimer's disease is a normal part of ageing. This was slightly lower than results from the Dementia Attitudes Monitor, which showed that 22% of people still believed dementia was a normal part of ageing.^{viii}

The results showed that 62% of those surveyed think that memory loss is an inevitable part of ageing. During the focus groups, this topic had been explored in more detail, with participants questioning what the symptoms of Alzheimer's disease were, asking, for example, whether forgetfulness (such as losing keys) is a key symptom.



As Alzheimer's disease was most commonly described in focus group meetings as memory loss that comes with ageing and a disease of the brain, this finding could be indicative of the fear experienced when an inevitable and harmless part of ageing becomes a symptom of Alzheimer's disease.

Knowledge of when Alzheimer's disease begins

Almost half of people surveyed agreed with the statement that *Alzheimer's disease begins decades before any symptoms emerge*, with only 12% disagreeing. This agreement rose to 58% and 60%

Alzheimer's disease begins decades before any symptoms emerge

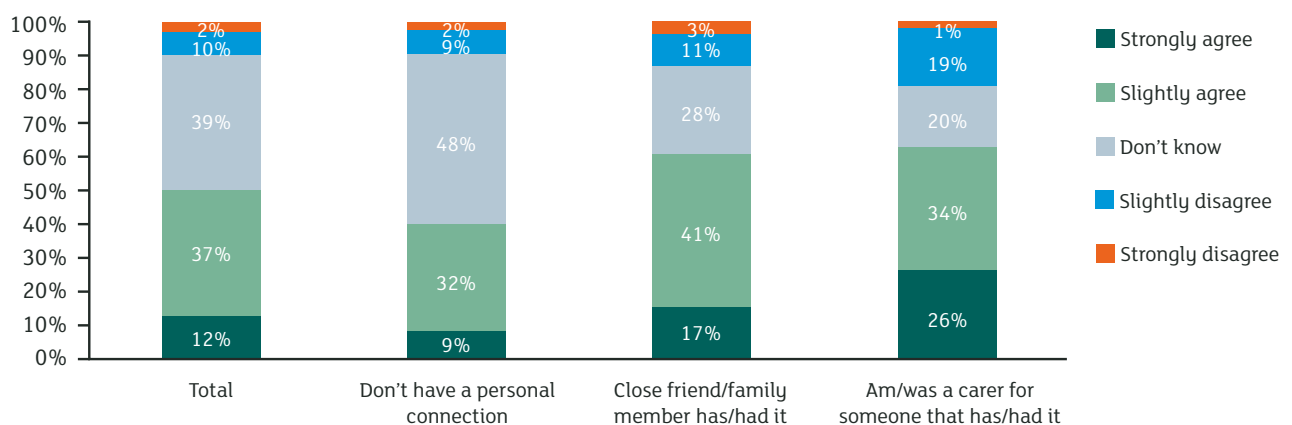
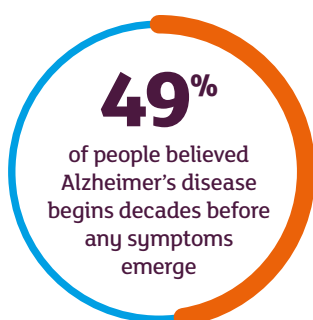


Figure 6: Early diagnosis of dementia survey, Populus (2019)

respectively for people who have experienced Alzheimer's disease or another form of dementia in a close friend or family member and for those who are or were carers, compared to 41% for people with no connection (Figure 6). There was also a notable difference in responses from different social grades, with 53% agreement among those in higher social grades (A, B, and C1) compared to 44% of people in lower social grades (C2, D and E).



While this is promising, there was a significant spread of views on this issue. We found 46% agreed that *Alzheimer's disease begins when symptoms start to emerge* and 24% agreed with the statement that *Alzheimer's disease begins when symptoms have reached a severe stage*. Again, there was a difference in responses across social grades in response to the latter statement, with 54% disagreeing among higher social grades, dropping to 49% disagreement among lower social grades. There was also variation in responses from different ethnic groups, with 49% disagreeing with this statement among white respondents, dropping to 37% disagreement among respondents from black, Asian and minority ethnic (BAME) backgrounds.

This indicates a mixed understanding of when Alzheimer's disease begins, across experiences of the disease, social background and ethnicities. While more people agreed with the statement that it begins before any symptoms emerge than any other statement included on this topic, the lack of clarity around the disease progression profile can be clearly seen, as the most popular answer to this statement was "don't know" (39%).

These findings are important to bear in mind when discussing attitudes towards risk factors and detection throughout the rest of this report: 51% of people surveyed did not know that the disease has a lengthy pre-symptomatic period.



Alzheimer's Research UK remains committed to working with the dementia community to co-create information that can be used to provide clarity on Alzheimer's disease both with patients and as part of an open dialogue with the public. Further information on this can be found at: <https://www.alzheimersresearchuk.org/about-dementia/quick-guide-dementia-translations/quick-guide-dementia/>

Recommendations

- 1 The NHS should make available **clear, accessible information on Alzheimer's disease and dementia**, including the differences between the two and the development of the disease from pre-symptomatic stage, through a range of communication channels.
- 2 The NHS should work with the dementia community to develop **guidance to support healthcare professionals' discussions about Alzheimer's disease and dementia** with patients and their carers and family. This should include guidance on appropriate language to use when discussing detection and diagnosis.

5. Detection and diagnosis of Alzheimer's disease

As part of our research, we wanted to understand more about public perceptions of the difference between detection and diagnosis of Alzheimer's disease, as well as attitudes towards the communication of risk, pre-symptomatic detection and investigations for a diagnosis of Alzheimer's disease. As this chapter sets out, our findings revealed notable variations in public understanding of the technical terms and processes used throughout the diagnosis pathway for Alzheimer's disease.

Detecting and diagnosing Alzheimer's disease: the difference

There is an important distinction to be made between the terms detection and diagnosis, especially in the context of Alzheimer's disease.

In Alzheimer's disease, detection refers to the identification of changes in the brain associated with the disease, such as the accumulation of amyloid. Currently, it is not possible to predict if or when the disease will develop once changes in the brain have been detected, as the accumulation of amyloid does not always lead to Alzheimer's disease. Detection would therefore only indicate whether an individual is at a higher risk of developing the disease.

The diagnosis of Alzheimer's disease occurs at later stages, when a clinical judgement of the presence of the disease is given to the patient. Diagnosis therefore currently takes place in the mild to moderate stages of the disease, when symptoms manifest. Current diagnosis of Alzheimer's disease depends largely on monitoring decline in cognition, at which point Alzheimer's disease has already caused significant and irreversible brain damage. However, research is advancing so that in future, diagnosis could happen earlier, prior to when symptoms occur.

To enable this, researchers are looking for an easy and accurate way to detect Alzheimer's disease before symptoms begin, during the pre-symptomatic stage.

The ability to detect those at risk of Alzheimer's disease would enable information about risk reduction to be targeted to those who could benefit most. Although there is currently no way to accurately predict disease, or to prevent dementia, there is information on measures that may reduce the risk of the condition. Many of the risk factors for dementia are the same as for cardiovascular disease. Maintaining a healthy lifestyle and exercising regularly will lower the risk of these diseases, and it is likely that it will lower the risk of dementia too. For more information on risk reduction, visit the Alzheimer's Research UK website: <https://www.alzheimersresearchuk.org/about-dementia/helpful-information/reducing-the-risk/>

Being able to detect and diagnose early offers a number of benefits to help individuals with Alzheimer's disease and their families. Due to the progressive nature of Alzheimer's disease, the best opportunity for individuals to benefit from treatments and enrol in clinical trials is in the early stages of the disease – the pre-symptomatic and prodromal stages.

Understanding of the definitions of detection and diagnosis

During the focus group discussions, the challenges of understanding the differences between the terms ‘detect’ and ‘diagnose’ were apparent. Many participants believed that these terms can be used interchangeably, which contrasts significantly with the way these terms are used within the research community. In particular, there was a lack of clarity about how and when detection and diagnosis happen, particularly as symptoms are seen to be day-to-day issues that are hard to distinguish as serious concerns. For example, some participants felt detection is the identification of symptoms at the first sign of confusion or memory loss. However, as noted earlier in the report, these symptoms are viewed by many to be a normal part of the ageing process.

On the whole, the focus groups revealed a preference for the use of ‘softer’ terminology when discussing detection, for example ‘find out’, ‘spot the signs’ and ‘pick up on’. The combination of a complex disease profile and the use of what can be perceived as ‘scary’ language contribute to the cycle of disengagement set out earlier in this report. In order to interrupt this cycle, there is a need for considered and careful communication with patients, carers and loved ones, as well as the public, when it comes to the complex process of detecting and diagnosing Alzheimer’s disease, and what each stage means for those involved.

“I think instead of detection you could say ‘spot the signs’. It’s a friendlier, less scarier, way of putting it.”
(Source: Populus 2019)

Attitudes towards communication of risk

When asked during the focus groups about the risk factors associated with developing Alzheimer’s disease, participants mentioned age, genetics and lifestyle factors – such as smoking, healthy eating and regular exercise – as known risk factors. When exploring the topic of risk further, there were clear concerns and confusion among participants about how risk could be controlled. There was a perceived lack of control associated with the concept of risk, with participants raising numerous questions:

- Does having elevated risk mean that you will get Alzheimer’s disease?
- How much of an elevated risk is needed before Alzheimer’s disease is detected?
- How can you tell whether you are positively impacting on risk factors by making lifestyle changes, when it can’t be measured?
- Would you have a responsibility to declare elevated risk factors, such as genetics, to the DVLA, your employer, your private healthcare provider or others? What sort of impact would this have?

On the whole, after discussing the topic during the focus groups, participants felt there was little perceived benefit to knowing if they had elevated risk, if there is nothing that can be done to manage it. However, there were a lot of questions on how to manage elevated risk, implying that more information would support greater understanding and acceptance of how to gain control – and therefore cope with the concept of elevated risk. This reveals a current gap in knowledge that can be filled to support informed joint decision-making between patients and healthcare professionals.

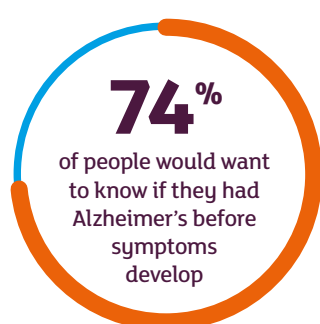
“I find being told you are at risk scary. I don’t know how to prevent or lower the risk so it makes me want to go into denial and switch off.”
(Source: Populus 2019)

“Can I change my outcome or level of risk?”

“How can I reduce my risk? Is it age or lifestyle? I need to know the facts or I will worry constantly.”

(Source: Populus 2019)

Attitudes towards pre-symptomatic detection of Alzheimer's disease



As well as exploring the concept of risk factors, we wanted to further understand public attitudes towards early and pre-symptomatic detection of Alzheimer's disease, years before the onset of dementia. Our public polling found that over two-thirds of people (74%) would want to know if they had Alzheimer's disease before symptoms appear. Breaking this down further, 38% would want to know 15 years before and 33% would want to know two years before. This level of support mirrors that identified in Alzheimer's Research UK's Dementia Attitudes Monitor Wave 1 Report.^{ix} However, there were some interesting differences among population groups and between the focus group and polling findings on this topic:

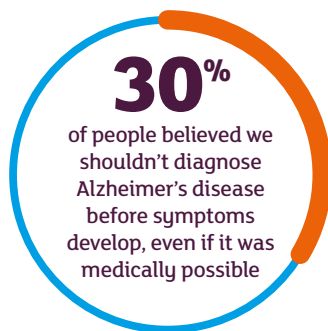
- There was a 10 percentage point difference in attitudes across social grades, with more people from higher social grades wanting to know 15 years before (42%), compared to lower social grades (32%).

- The most common spontaneous response during the focus groups was that tests should be used when symptoms start to appear, but only 15% of people surveyed said that they would not want to know if they had Alzheimer's disease before symptoms appear.
- When discussing timing for pre-symptomatic detection, the polling revealed a preference for knowing fifteen years before symptoms, whereas in the focus group discussions, there was a preference towards detection two years before symptoms appear, to allow them to get “everything in order and live life to the fullest”. Fifteen years was seen as a prolonged period of worry and fear: “15 years. It's almost like a prison sentence hanging over your head, isn't it?” (Source: Populus 2019).

On the whole, the focus group discussion indicated stronger support for early detection when people had more certainty about their level of risk. This can help people to gain control over their situation, either as patients, carers or family members, breaking the cycle of disengagement that is associated with Alzheimer's disease.



Attitudes towards investigation for a diagnosis



Our survey asked whether people agreed with the statement *even if it's medically possible, we shouldn't diagnose someone with Alzheimer's disease before symptoms develop*. The results showed 44% of people rejected the statement, rising to 50% for carers. Less than a third (30%) of people agreed with the statement (Figure 7). Uncertainty also decreased among those with a connection to the disease, from 32% among those with no connection through to 15% among carers, as demonstrated in Figure 7. There was notable variation between ethnic groups as well, with 29% of respondents from white ethnic backgrounds agreeing with this statement, compared to 40% agreement from respondents from BAME backgrounds.



“[The word] diagnosis is good to use as it's acknowledgement of getting Alzheimer's. It's a clear confirmation.”
(Source: Populus 2019)

Even if it's medically possible, we shouldn't diagnose someone with Alzheimer's disease before symptoms develop

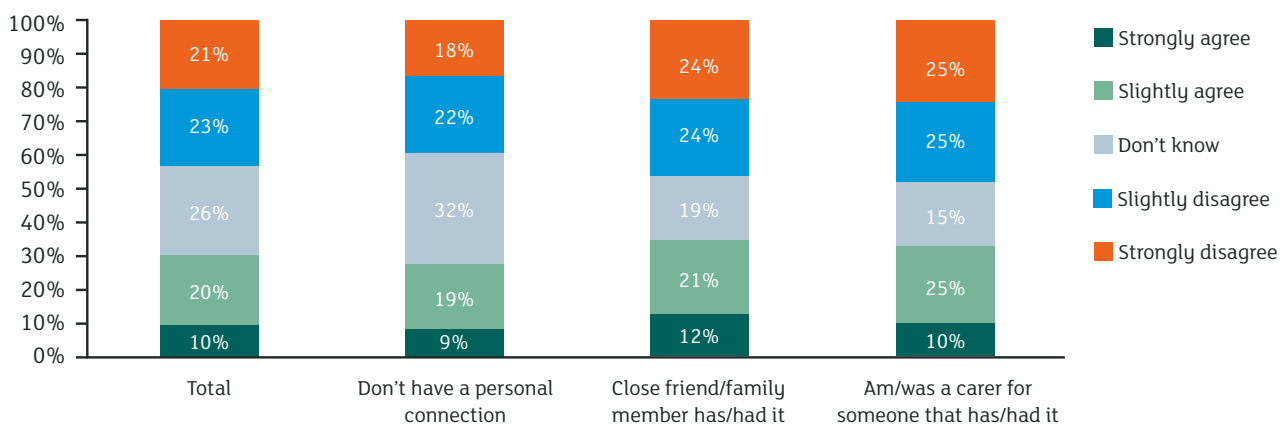


Figure 7: Early diagnosis of dementia survey, Populus (2019)

It doesn't matter if someone is diagnosed with Alzheimer's disease because there is nothing we can do to help them

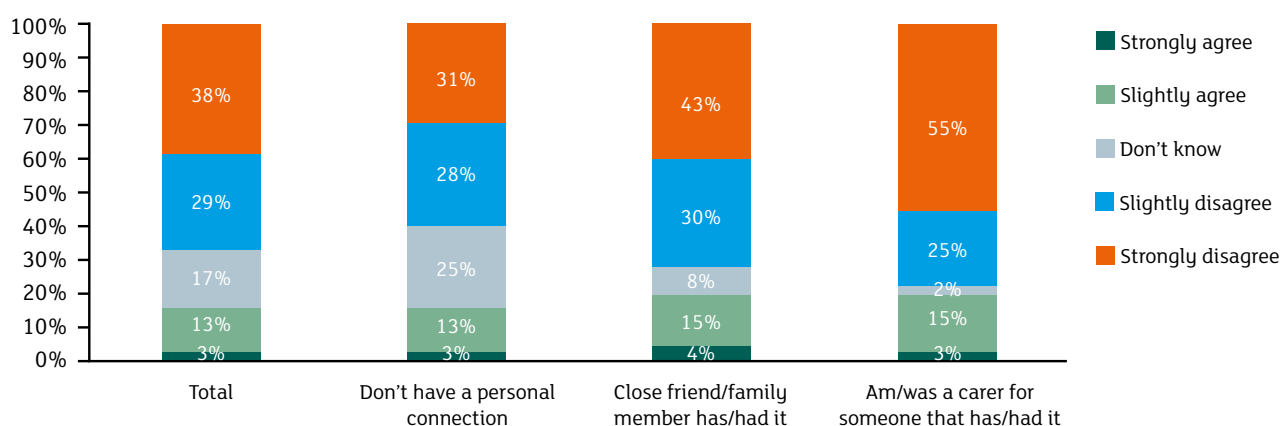


Figure 8: Early diagnosis of dementia survey, Populus (2019)

We also asked whether people agreed with the statement *it doesn't matter if someone is diagnosed with Alzheimer's disease because there is nothing we can do to help them*. In the polling, 67% of people disagreed, again rising to 80% for carers. Only 16% agreed with the statement (Figure 8). There was variation in responses across age groups, with 22% of younger respondents (18-34) responding "don't know" compared with only 15% of older respondents (55+). Again, there was more certainty among people who have a connection with dementia: respondents answering "don't know" reduced from 25% in those with no connection, down to 2% for carers, as shown in Figure 8.

In the focus groups, the term 'diagnosis' was received more confidently and positively than 'detection' as it brought with it more certainty – a theme that had emerged in discussions around elevated risk and detection. However, psychological and emotional support during both detection and diagnosis was seen as crucial, before, during and after the process. As with the discussion on elevated risk, many questions were raised around:

- What detection means.
- What the next steps would be, including timing before a diagnosis.
- What support is available post-detection and post-diagnosis.
- Information around the tests for a definite diagnosis.
- Information about Alzheimer's disease itself, including how quickly it progresses.

These are all areas where improved communication would support informed discussions between patients and their healthcare professionals.

Recommendations

3 The NHS should work with patient groups and charities to develop **more accessible information for the public on how Alzheimer's disease is currently diagnosed**, including information about the most effective and accurate tests, and the benefits of early diagnosis.

4 The research and health communities, in conjunction with patient and public representatives should agree **a common and consistent language to describe detection and diagnosis of Alzheimer's disease**. These communities should also work together to establish a greater understanding of the stage at which diagnoses are currently being made, for example through an agreed definition of the language, stages of progression and methods of analysis.

5 The NHS should **include conversations about risk factors and wider brain health as standard during any appropriate interaction**, including routine NHS and non-NHS health checks.

6. Public attitudes towards diagnostics and testing

Our survey asked respondents how willing they would be to undertake existing and potential future tests to identify their risk of developing Alzheimer's disease. To do this, we split our respondents into two equal cohorts: one cohort was informed that there are no treatments available to slow down or cure Alzheimer's disease; and one was told of potential new treatments being developed that rely on treating the disease early, with a hypothetical scenario that these were available.

This chapter looks at cohort one, who were told that there are no treatments available. The following chapter explores cohort two, responding to there being a hypothetical treatment available.

On the whole, people were willing to undertake most forms of testing to help identify the risks of developing Alzheimer's disease (over 75%).

The exception to this was cerebrospinal fluid (CSF) sampling: 40% of those surveyed agreed that they were willing to undertake this test (Figure 9), mirroring the results of the Dementia Attitudes Monitor Wave 1 Report (44%).^x

How willing would you be to have each of the following tests to help identify your risk of developing Alzheimer's disease? (No treatments)

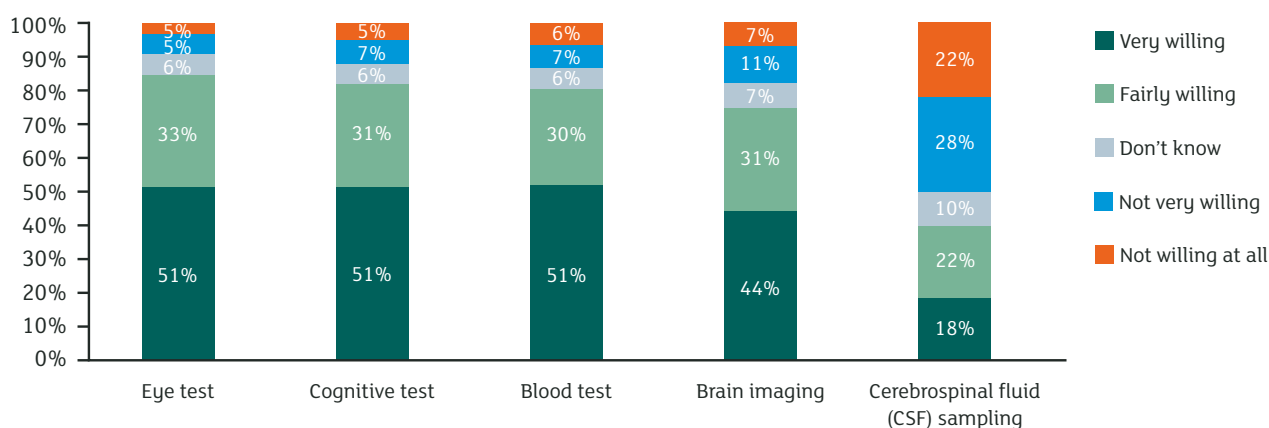


Figure 9: Early diagnosis of dementia survey, Populus (2019)

Detection and diagnostic tests for Alzheimer's disease

Changes in the brain can happen as many as 20 years before any symptoms of Alzheimer's disease appear. There are tests in development to detect these early changes in the brain, which will provide information on the risk of developing Alzheimer's dementia. These tests would be administered in the pre-symptomatic stage.

There are also tests to diagnose Alzheimer's disease, which are administered when symptoms become apparent – between the prodromal and mild to moderate stages.

Below is a summary of the current tests available for detection and diagnosis of Alzheimer's disease:

Test	Detection	Diagnosis	In Development
Cognitive test		☐	
Brain imaging Brain structures (MRI and CT scan)		☐	
Brain imaging Disease processes (PET scan)	☐	☐	
CSF sampling	☐	☐	
Blood test			☐
Eye test			☐

Cognitive test – to check cognitive abilities, such as memory or thinking.

Brain imaging – produces detailed images of the brain through scanning.

Cerebrospinal fluid (CSF) sampling – collection of fluid from the spinal cord (also known as a lumbar puncture) using a thin needle to detect the proteins associated with Alzheimer's disease.

Blood test – collection of blood samples to detect proteins associated with Alzheimer's disease.

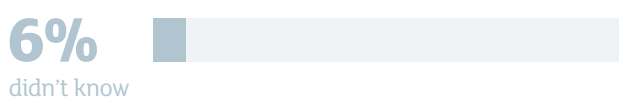
Eye test – eye scan that identifies structural changes potentially associated with Alzheimer's disease.

Attitudes towards different tests

Respondents were more willing to undertake tests that are perceived as less invasive and that people are more familiar with, for example eye tests and blood tests. During the focus groups, participants noted that their decision on whether

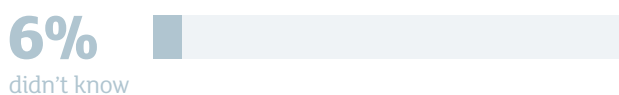
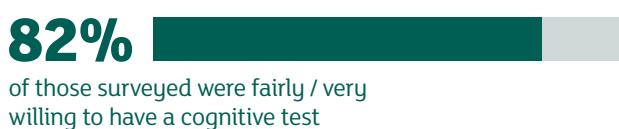
to undertake a test or not would be influenced by a healthcare professional, indicating the importance of the clinical voice in attitudes towards the tests in question. Responses to each of the tests are explored in more detail below.

Eye test



Eye tests were the most accepted method of testing among the general public, with 84% of those surveyed saying that they would be willing to undergo this test to identify the risk of developing Alzheimer's disease – even though there are no treatments available. Eye tests were perceived to be non-invasive and easy to complete, and most people have already experienced an eye test in the past, so knew what to expect. There was minimal fear or worrying prompted by the thought of an eye test. However, participants did question the accuracy and credibility of this test for detecting or diagnosing Alzheimer's disease.

Cognitive test



Cognitive testing was felt by participants in the focus groups to be the easiest and most non-invasive test. This was reflected in the high willingness among survey respondents (82%) to undertake this test to help identify the risk of Alzheimer's disease. In terms of access, focus group participants believed they could be scheduled in quickly and undertaken very easily. However, the cognitive test was understood to be part of an initial investigation, rather than early identification of risks or a definite diagnosis. This understanding could be linked to the predominant view that memory loss is an inevitable part of ageing, rather than a definitive indicator of Alzheimer's disease.

There were also concerns raised that there could be significant barriers to the accuracy of this test, including cultural and language barriers. It was therefore not deemed to be a credible test for providing a definitive diagnosis.

Blood test

81%

of those surveyed were fairly / very willing to have a blood test

6%

didn't know

13%

were not at all / not very willing

Brain imaging

75%

of those surveyed were fairly / very willing to have an MRI / PET scan

7%

didn't know

18%

were not at all / not very willing

Cerebrospinal fluid (CSF) sampling

40%

of those surveyed were fairly / very willing to have an CSF

10%

didn't know

50%

were not at all / not very willing

Figures taken from Populus Survey, 2019

Blood tests were also among the most acceptable methods for identifying the risk of Alzheimer's disease. Similar to the eye test, the blood test was perceived positively in the focus group discussions, with every participant having experience of blood tests in the past. There was therefore a familiarity with the procedure, and it was perceived to be non-invasive and easy to take. Again, there was minimal fear associated with blood tests, with only the fear of needles being raised during discussions. However, as with both the eye test and cognitive test, the accuracy and credibility of the blood test were questioned.

While not as popular as eye, cognitive and blood tests, three-quarters of those surveyed said that they would be willing to have an MRI or PET scan to identify their risk of Alzheimer's disease. **Brain imaging** was also seen as one of the most acceptable tests during the focus group discussions. Unlike the previously discussed tests, this was seen by attendees to be accurate and very credible, producing a reliable and definite result. There was also high awareness of what MRI and PET scans are, and no issues were raised during the focus groups regarding travelling to undergo these tests. They were perceived to be non-invasive and painless, although some fear of claustrophobia was noted.

In contrast to the other tests, 40% of those surveyed said that they would be willing to undertake **CSF sampling** to identify their risk of Alzheimer's disease. There was a notable split in responses between men and women: on the whole men were more willing (48%) to undergo CSF sampling than women (37%). The focus groups explored reactions to CSF sampling in more detail, to understand the associations: as with the polling results, CSF sampling was seen by participants as the least acceptable test overall, with participants associating it with high levels of pain, worry and anxiety. Issues around safety were also raised, such as perceptions of spine damage. Participants were familiar with the term lumbar puncture, but considered it to be invasive and painful. As with brain imaging, the accuracy of the test is thought to be high, but through discussion, many participants felt it not to be worth the psychological worry or physical pain to consent to the test.

Discussion

There is optimism among the scientific community, based on the latest research findings, that detection techniques may develop rapidly in the next few years. There may be the potential to develop innovative techniques that combine multiple indicators to create a risk profile for Alzheimer's disease. There is also growing evidence that blood-based biomarkers may well be clinically available as a detection method for Alzheimer's disease within the next five years. Blood-based detection methods are likely to be much easier to scale up, could be performed by many healthcare professionals and have good public acceptance.



Although the methods for measuring proteins in the blood have improved dramatically, these are still not as accurate as tests of spinal fluid, therefore any future introduction of blood sampling is likely, in the short term at least, to be a first stage test. Therefore, CSF sampling is likely to have an important role in identifying pathological changes in the brain prior to symptoms. We also need to challenge assumptions that CSF is a painful procedure or that it carries significant side effects. Lessons could therefore be learnt from other tests (such as endoscopies) and other treatments (such as the epidural) that are more invasive, as well as lessons from differing clinical perspectives of these tests.

These lessons would be valuable in understanding how to develop communications to support discussions about CSF sampling, both among the public but also between patients and their clinicians. The role of the clinical voice both in shared decision-making and in shaping public

perceptions and acceptance of different diagnostic techniques is vital. It is therefore important to understand the range of clinical views on this topic, and ensure that healthcare professionals are given the tools to help patients make informed choices.

In addition, given the concerns about accuracy with some of the other tests that are more acceptable to the public, alongside an existing expectation that a series of tests will be required to diagnose Alzheimer's disease, consideration should also be given to using these other, less-invasive tests as part of a risk stratification process before undergoing CSF sampling. This could increase willingness to consent to the test – and confidence in the test itself – if other tests had indicated the need for further investigation. Introducing such a process may also prove beneficial in adopting new diagnostic options that become available. This is a rapidly-evolving research area and new developments – for example potential digital monitoring – could move the goalposts for which tests are integrated into the pathway in ways we may not currently expect or anticipate.

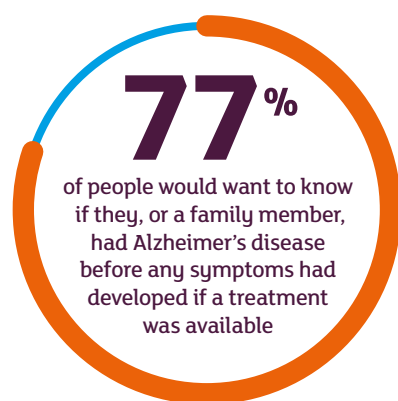
Recommendations

- 6** The NHS should **pilot a risk-stratified approach towards diagnosis**, with the aim of increased use of appropriate diagnostics (such as CSF or blood tests in due course) earlier in the disease progression.
- 7** The NHS and dementia community should work together to develop an action plan of **communications and engagement activities and opportunities to improve public understanding of CSF** and its role in detecting Alzheimer's disease.
- 8** The dementia community should seek to **better understand current clinical perceptions towards the tests used to detect and diagnose Alzheimer's disease** and the key role they play in patient attitudes.

7. The implications of new treatments

As more information emerges on the causes of Alzheimer's disease and how to identify the early, pre-symptomatic changes in the brain, more research is being focused on effective ways to slow down – or even halt – the development of the disease. New treatments, particularly disease-modifying, are most likely to be effective if they are initiated as early as possible in the disease pathway. Early detection and diagnosis is therefore crucial both to supporting research into potential new treatments, and for when those treatments become available, making sure that patients can access them at the earliest stage possible.

This chapter focuses on findings from cohort two. These respondents were told of potential new treatments being developed to slow down or delay the onset of Alzheimer's disease that rely on treating the disease early, and asked to respond in the context of a hypothetical scenario that these were currently available. This allowed us to compare the impact of future treatments on public attitudes.



On the whole, the findings from this cohort of responses indicated an increase in demand for earlier detection and diagnosis should a treatment be available, and a current need for changes in the healthcare system to support earlier detection and – where possible – diagnosis of the condition at a pre-symptomatic stage.

When asked whether they would want to know if they, or a family member, had Alzheimer's disease before any symptoms had developed, 70% of polling respondents said yes. This increased to 77% for those asked the same question, but in the hypothetical situation that **treatments were available**.

Similar results were seen when we asked if they would want to know if they, or a family member, had a heightened chance of developing Alzheimer's disease: 68% of people said they would want to know, rising to 75% in the group asked to consider their response **if some treatments were available**.

The polling demonstrates that the majority of people would want to know, regardless of whether treatments are available, if they or a family member had either a heightened risk of developing Alzheimer's disease or had already developed pre-symptomatic Alzheimer's disease. As previously mentioned, focus group participants were more cautious towards the concept of pre-symptomatic detection.

However, when asked whether they would be more willing to find out if they had pre-symptomatic Alzheimer's disease if there were potential treatments, these participants were significantly more likely to opt for finding out two years before symptoms appeared. The differences between the reaction in focus group discussions and the polling data suggests that in-depth discussions have an important effect on people's attitudes. Informed consent is therefore of particular importance when exploring pre-symptomatic detection and diagnosis.



Impact on attitudes towards testing

How willing would you be to have each of the following tests to help identify your risk of developing Alzheimer's disease?

Test	Willing despite no treatments	Willing with potential treatments
Eye test	84%	88%
Cognitive test	82%	87%
Blood test	81%	85%
Brain imaging	75%	79%
CSF sampling	40%	43%

Populus Survey, 2019

When looking at people's willingness to undertake specific tests in the polling, this increased across the board among those who were asked to imagine that treatments were available. However, willingness to undergo CSF sampling does remain below 50% and only increased by 3% with treatments available, where most other tests increased by 4-5%. The same considerations therefore apply around a risk stratified approach to testing, combined with informed decision-making between patients and their healthcare professionals when discussing detection and diagnosis. What is notable, nevertheless, is that there is already a clear willingness among the public to undergo tests to identify the risk of developing Alzheimer's disease, regardless of whether there is a treatment available.

We recognise that new treatments for Alzheimer's disease could radically change current diagnostic and care pathways, and therefore we need to start considering how the health service could respond. Building on existing insight we need to work collaboratively to develop new approaches to help meet this challenge.^{xi,xii} This could include piloting brain health clinics, which could have the potential to offer a holistic approach to detection and earlier diagnosis of Alzheimer's disease, the chance to offer risk reduction interventions and opportunities to participate in research.

Recommendations

9

The Department of Health and Social Care should undertake work to **prepare the healthcare sector to be able to detect the diseases that cause dementia 10-15 years before symptoms appear**. This includes horizon scanning of diagnostic techniques that could be used at scale.

10

The Department of Health and Social Care should undertake modelling into what **changes are needed in the diagnostic pathway to support access to both current symptomatic treatments and future treatments** – whether symptomatic or disease-modifying. For example, this could include piloting brain health clinics as a new service model for detection and earlier diagnosis of Alzheimer's.

8. Conclusion

Alzheimer's disease is a complex condition, and for many people a highly emotional issue. There is still much to be learnt about the disease profile, which can often lead to confusing and conflicting information for patients, their carers and loved ones, and the public. This report has sought to bring to light some of these points of confusion, as well as attitudes towards dementia and Alzheimer's disease including the process of detection and diagnosis.

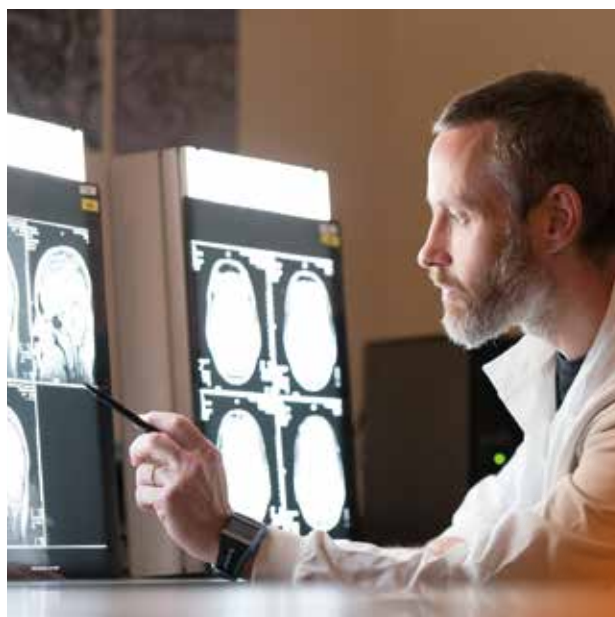
There is high awareness among the public that there is no life-changing treatment or cure for the condition. Combined with the confusing – and often uncertain – nature of the disease, this contributes to a cycle of disengagement when discussing Alzheimer's disease and dementia: fear, confusion, perceived lack of control and disengagement. Each stage of this cycle is a barrier to open dialogue about dementia and Alzheimer's disease that must be overcome through a combination of research, improved communication, informed decision-making and clear processes for earlier detection and diagnosis.

There is a clear need for improved dialogue around Alzheimer's disease and dementia, from information about the condition and its risk factors, through to the detection and diagnosis pathways available now and in the future for Alzheimer's disease. This report has highlighted some of the variations in attitudes and awareness across different social grades, ethnicities and connections to dementia, indicating that information needs to be accessible to all audiences. The clinical voice is crucial here to support patients to make informed decisions.

As scientific evidence supports greater research into new treatments earlier in the Alzheimer's disease pathway, more is now needed to implement earlier detection and diagnosis both to contribute to this research, but also to support people to make informed choices about their – or their loved ones' – care. Our research has found that most people would want to know whether they have an increased risk of developing Alzheimer's disease

and believe that, even with no treatment available, people should be able to find out at an early stage whether they have the disease. More certainty, where possible, helps to empower people and their carers or loved ones to gain greater control over their situation.

Moreover, the results from public attitudes towards testing shows that most tests are acceptable to the public, but for the most accurate and cost-effective test – CSF sampling – a risk-stratified approach would be more appropriate. More action must now be taken to put in place the infrastructure to support earlier diagnosis. This should include understanding current capacity and then outlining current and future detection and diagnostic pathways.



9. Summary of recommendations

Throughout this report we have made a number of recommendations for how the NHS can better support people to receive an early diagnosis and live as well as possible with their condition. These recommendations can be grouped into three core themes:

Improving communication with patients and the public

1. The NHS should make available **clear, accessible information on Alzheimer's disease and dementia**, including the differences between the two and the development of the disease from pre-symptomatic stage, through a range of communication channels.
2. The NHS should work with the dementia community to develop **guidance to support healthcare professionals' discussions about Alzheimer's disease and dementia** with patients and their carers and family. This should include guidance on appropriate language to use when discussing detection and diagnosis.
3. The NHS should work with patient groups and charities to develop **more accessible information for the public on how Alzheimer's disease is currently diagnosed**, including information about the most effective and accurate tests, and the benefits of early diagnosis.
5. The NHS should **include conversations about risk factors and wider brain health as standard during any appropriate interaction**, including routine NHS and non-NHS health checks.
6. The NHS should **pilot a risk-stratified approach towards diagnosis**, with the aim of increased use of appropriate diagnostics (such as CSF or blood tests in due course) earlier in the disease progression.
7. The NHS and dementia community should work together to develop an action plan of **communications and engagement activities and opportunities to improve public understanding of CSF** and its role in detecting Alzheimer's disease.
8. The dementia community should seek to **better understand current clinical perceptions towards the tests used to detect and diagnose Alzheimer's disease** and the key role they play in patient attitudes.

Supporting earlier detection and diagnosis

4. The research and health communities, in conjunction with patient and public representatives should agree **a common and consistent language to describe detection and diagnosis of Alzheimer's disease**. These communities should also work together to establish a greater understanding of the stage at which diagnoses are currently being made, for example through an agreed definition of the language, stages of progression and methods of analysis.
9. The Department of Health and Social Care should undertake work to **prepare the healthcare sector to be able to detect the diseases that cause dementia 10-15 years before symptoms appear**. This includes horizon scanning of diagnostic techniques that could be used at scale.
10. The Department of Health and Social Care should undertake modelling into what **changes are needed in the diagnostic pathway to support access to both current symptomatic treatments and future treatments** – whether symptomatic or disease-modifying. For example, this could include piloting brain health clinics as a new service model for detection and earlier diagnosis of Alzheimer's.

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Notes

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