



# Tackling the challenges of getting a **timely diagnosis** for Alzheimer's disease

Report on February 21st 2022 webinar



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## Introduction

Patients with Alzheimer's disease (and other forms of dementia) face many challenges in getting the right level of support—as do their carers and families. Such support, however, can only be provided on diagnosis, which can make a huge difference to a person's eventual quality of life, but is too often missed.

As the incidence of dementia rises exponentially worldwide, alongside the burden of care, PatientView, with sponsorship from Novo Nordisk, decided to explore the factors that prevent timely diagnosis and what could enable it, by holding an international interactive webinar on February 21st 2022. Four experts, with different areas of expertise, were invited to share their views with 17 representatives of carer/patient advocacy groups from 10 different countries (see end of introduction for biographies of the four panellists a list of attendees).

PatientView is a company with over 20 years' experience of collating and disseminating the opinions of all patient organisations, including those dealing with Alzheimer's disease and other dementias. Novo Nordisk has a specific interest in the topic as it has a potential Alzheimer's disease treatment in clinical study.

### About the webinar and its aims

The discussion aims to improve understanding of how timely diagnosis can be achieved on a national but also an international scale, and the role of patient advocacy groups have in supporting this goal.

*In the rest of this report you will find:*

- The main themes and discussions that took place at the February 21st 2022 webinar
- Executive summary and final takeaway messages

The full recording can be found on PatientView's website: [www.patient-view.com](http://www.patient-view.com).

To set the scene, each of the four experts describe **what single factor would make the biggest difference in terms of timely diagnosis for Alzheimer's disease in five years' time?**



**Paola Barbarino**  
Chief Executive Officer  
Alzheimer's Disease International  
(ADI)



**Michael Hornberger**  
Professor of Applied Dementia  
Research  
Norwich Medical School, UEA



**Dr Fábio Porto**  
Scientific Director  
Associação Brasileira de Alzheimer  
(ABRAz), São Paulo



**John Schall**  
Chief Executive Officer  
Caregiver Action Network, USA

**Paola Barbarino,**  
Chief Executive Officer,  
Alzheimer's Disease  
International (ADI).

Based in the UK. ADI is the global umbrella body, which represents 105 national Alzheimer organisations from around the world. Barbarino hopes that healthcare systems worldwide will change their approach to tackling dementia:

"It would be wonderful to see a change in attitude, both in governments and healthcare professionals. In 2019, ADI found that 62% of healthcare professionals still believed that dementia was caused by normal ageing. That demonstrates the scale of the challenge, when 62% of people don't even think it is a disease. There are therapeutic breakthroughs on the horizon, important ones, and what we have found in a number of our studies and research is that there is a very poor level of preparedness by governments, in both high-income and low-income countries, with some notable but very few exceptions. We need to heighten awareness in primary care and government preparedness."

**Michael Hornberger,**  
Professor of Applied  
Dementia Research, at  
Norwich Medical School, UK  
hopes that the availability  
of new technologies should  
transform the ease and  
accuracy of diagnosis of  
Alzheimer's disease:

"I would like to see more personalised diagnostics. I think that will be key to future progress – it will make a particularly huge difference in prevention or risk reduction approaches. Also, if you get a diagnosis, you need to know which type of dementia (you have). There is such a misunderstanding, even at our health care level about the different types of dementia being quite different diseases and, of course, this affects the choice of treatment."

**Dr Fábio Porto,**  
Scientific Director of  
Associação Brasileira  
de Alzheimer (ABRAz),  
São Paulo, Brazil, and  
Neurologist, like Barbarino,  
sees the need to educate  
primary care doctors, in  
particular, about the realities  
of Alzheimer's disease and  
other dementias:

"Early diagnosis is a problem in Latin America because doctors, mainly primary care family doctors, believe that memory problems are due to normal ageing, that dementia is something that occurs with ageing, and it's not a disease. Sometimes these beliefs are difficult to change because people learn, doctors have learned this in the past. What we want to do is provide medical education and increase awareness among doctors and the public. ABRAz is trying to do this because early diagnosis will be important as new drugs, new treatments become available."

**John Schall,**  
CEO of Caregiver Action  
Network, USA, the leading  
consumer facing non-profit  
organization representing  
the interests of family  
caregivers, also hopes  
that family caregivers will  
embrace the fact that timely  
diagnosis of Alzheimer's  
disease is a positive, not a  
negative:

"What I would most like to see in the next five years is the reticence, the hesitation, the feeling of resignation, on the part of families go away in terms of trying to get an early diagnosis of their loved ones with Alzheimer's disease...So really, to put this mental state of resignation behind us until much further along in the process."

## List of the attendees at the 21st February 2022 webinar

(Who are happy to be named)

<b>CANADA</b> France Boisclair Presidente Regroupement des Aidants Naturels du Québec	<b>PORTUGAL</b> Catarina Alvarez Responsável pelas Relações Institucionais Associação Alzheimer Portugal	<b>SPAIN</b> Carmen Jose Ruiz Pareja Manager Alzheimer Soria	<b>UK</b> Alison McKean AHP Post Diagnostic Lead Alzheimer Scotland
<b>CZECH REPUBLIC</b> Veronika Raszková Manager, counsellor, social worker Slezská diakonie	<b>SLOVENIA</b> Nika Antolašić Secretary Zveza društev upokojencev Slovenije	<b>UK</b> Rosie Houghton Corporate Partnerships Manager Alzheimer's Disease International (ADI)	<b>UK</b> Carol Munt Independent
<b>ITALY</b> Gioele Petrelli Psychologist AFAM Alzheimer Uniti Marche	<b>SPAIN</b> Jesus Rodrigo CEO CEAFA: Confederacion Española de Asociaciones de Familiares de Personas con Alzheimer y otras Demencias	<b>UK</b> Kelly Baya Dementia Team Leader Age UK	<b>USA</b> Karen Weyrauch COO - DAC Healthcare System Preparedness Davos Alzheimer's Collaborative
<b>LUXEMBOURG</b> Cindy Birck Project officer Alzheimer Europe	<b>SPAIN</b> Álvaro del Corral Neuropsychologist Fundación Alzheimer España	<b>UK</b> Elaine Hunter AHP Consultant Alzheimer Scotland	<b>USA</b> Ian Kremer Executive Director LEAD Coalition

### Footnote

The views expressed in the report do not necessarily reflect those of PatientView and the funding sponsor Novo Nordisk.

# Tackling the challenges of getting a timely diagnosis for Alzheimer's disease

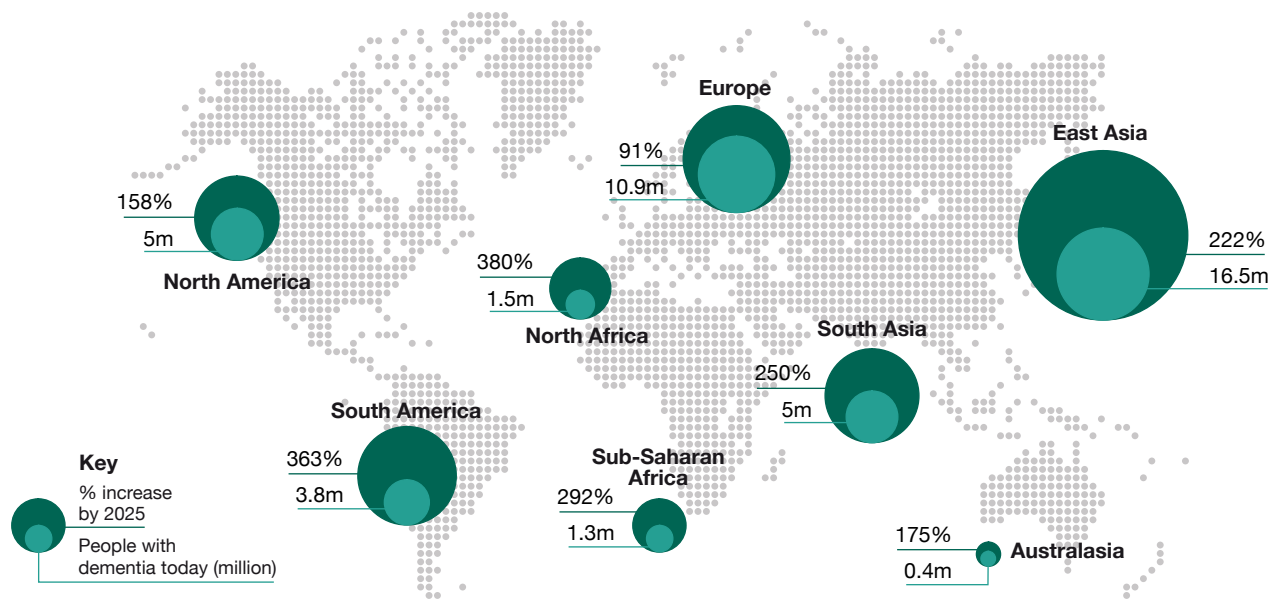
## Content and key themes of the webinar

During the 90-minute February 21st webinar, panellists dealt with a range of key topics, such as explaining why the process of attaining a timely diagnosis in Alzheimer's disease is so elusive; about the necessity to overcome the challenges faced in getting a timely diagnosis; and the role of carer/patient advocates in attaining that goal.

The topics included:

- The global scale and social/financial impact of Alzheimer's disease, now and in the future.
- The significant challenges in obtaining a timely diagnosis.
- How poor understanding of Alzheimer's disease and dementia hinders timely diagnosis.
- How faulty memory may not always be a signal of dementia.
- The need for scientific consensus of the patient pathways for Alzheimer's disease.
- Why timely diagnosis can improve patient outcomes.
- How several new technologies can support timely diagnosis of Alzheimer's disease.
- The need for civil society to influence political decision-makers.

## A global epidemic with a heavy cost, 2015 to 2050



Source: <https://www.fic.nih.gov/News/GlobalHealthMatters/march-april-2015/Pages/nih-alzheimers-research-summit.aspx>

According to the World Health Organization<sup>1</sup> the number of people currently living with dementia (including Alzheimer's disease) across the world has reached epidemic levels. By 2019, a total of 55 million people are thought to live with dementia.<sup>2</sup> The prevalence of those living with dementia challenge is set to rise dramatically by 2050, particularly in low and middle income countries. In North Africa, for example, cases are expected to almost quadruple.<sup>3</sup>

The social and financial implications of this epidemic are already significant, only to be magnified with each decade. In the US alone, 2021 estimates are that 15 billion hours of care are required each year to look after patients with Alzheimer's disease (the more common form of dementia) at a cost of a quarter of a trillion dollars.<sup>4</sup>

*"Even by US standards, a quarter of a trillion dollars is a lot of unpaid care that's being provided,"* says John Schall, CEO of Caregiver Action Network, the leading consumer-facing non-profit organisation in the US representing the interests of family caregivers.

He adds the toll that Alzheimer's disease takes on families, friends and caregivers is significant. *"Family caregivers will suffer higher levels of depression because of a loved one with Alzheimer's. They have tremendous disruptions in their jobs or careers. They sacrifice financially, as they meet a lot of costs out of their own pockets. And there is certainly a significant emotional cost."*

### The challenges in obtaining a timely diagnosis

To help set the agenda for the webinar of February 21st 2022, PatientView conducted a small survey of 13 patient/carers groups from Bulgaria, Canada, France, India, Italy, Spain, UK and Zimbabwe. All had experience of dementia and/or Alzheimer's disease. These patient groups were questioned on the challenges faced in obtaining a timely diagnosis of Alzheimer's disease. The respondent identified various barriers to a timely

diagnosis [see Appendix], which could be categorised into four types: barriers for (1) Patient/carers (2) Health professionals (3) Healthcare systems and (4) Treatment and diagnosis.

Paola Barbarino, Chief Executive Officer of Alzheimer's Disease International, noted that accessing a timely diagnosis can be a universal struggle: *"I live in the UK. Many of my friends with family who find themselves with a possible loved one with Alzheimer's disease, unfortunately, do not have the opportunity to access a timely diagnosis, even in a country that has the possibility of delivering that. Often primary care doctors are themselves not aware of the signs and symptoms of the disease, but also because of the absence of PET scanners, CT scanners, any kind of diagnostics, or doctors who are sufficiently trained in that area. So, we have a massive challenge."*

### Misconceptions about Alzheimer's disease

According to Schall, the significant care burden is not helped by the fact that those diagnosed with dementia feel a sense of resignation and hopelessness, underpinned by a lack of understanding about the disease itself. People are often reluctant to come forward for diagnosis: *"From the family's perspective, this feeling of hopelessness and resignation keeps you back from trying to get an earlier diagnosis. It does not help that a lot of the primary doctors also have this feeling of hopelessness. Primary care physicians don't as often engage in conversations about Alzheimer's as they should, thinking there's not much that can be done."*

Misconceptions about Alzheimer's disease reinforce the negative connotations of getting a diagnosis—for example, the idea that the disease proceeds quickly, causing a rapid downhill slide in all aspects of a person's cognitive abilities. *"But that's just not true,"* says Schall. *"There can be cognitive impairment in some functional areas, but not necessarily in others – every case is different."* Such presumptions can lead to erroneous

1 [https://www.who.int/ageing/publications/global\\_health/en](https://www.who.int/ageing/publications/global_health/en)

2 <https://apps.who.int/iris/rest/bitstreams/1367115/retrieve>

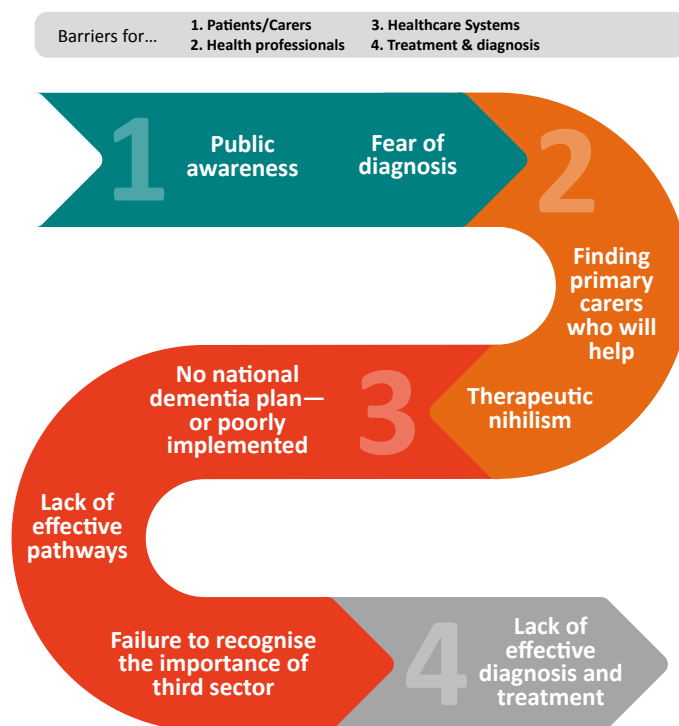
3 [https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667\(21\)00249-8/fulltext](https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(21)00249-8/fulltext)

4 <https://www.alz.org/alzheimers-dementia/facts-figures>



## Challenges in attaining a timely diagnosis of Alzheimer's disease as identified by carer/patient groups

Source: PatientView, 2022



decision-making in future life planning—regarding employment status, or determining appropriate treatment paths with doctors and families, says Schall.

As mentioned at the start of the webinar, there is also the misconception that dementia is merely a normal part of ageing. In 2019, Alzheimer's Disease International (ADI) found that 62% of healthcare professionals who responded to a survey for the 'World Alzheimer Report 2019: Attitudes to dementia' believed that dementia is a part of normal ageing, and is not a disease. Commenting on this, Schall says *"It's a huge problem obviously, but what also goes along with that, from the family caregiver's perspective, is unnecessary and wrong – a genuine, real feeling of hopelessness about the situation when there's, really, so much that can be done."*

Dr Fábio Porto, Scientific Director of Associação Brasileira de Alzheimer, São Paulo and Neurologist, speaking about those who witness cognitive decline within their families: *"My impression is that it's a kind of euphemism: 'if it's not (dementia) then I don't need to care. It's not a problem.' But this always makes the suffering (eventually) greater. If you don't (accept) something is happening, you don't have time to prepare and you don't have access to treatments or psychoeducation to know how to deal with behaviour problems or how to deal with the memory and the other cognitive issues."* This low level of knowledge and awareness also extends to the medical community, he says. [See Case study – Dementia in Brazil, page 15].

### The problem of focusing solely on memory impairment to diagnose Alzheimer's disease

Michael Hornberger, Professor of Applied Dementia Research, Norwich Medical School, says there is a need to educate people about dementia, and explain what constitutes an attention or memory problem. He maintains that too often people think ordinary forgetfulness, such as walking into another room to get something and forgetting what they wanted, is a classic sign of dementia. He adds, it can be very difficult to distinguish between healthy memory loss – such as forgetting your glasses are on the top of your head – and symptoms of Alzheimer's, particularly with elderly patients. *"When it comes to the cognitive aspect of dementia, this is an area where, as a scientist, I despair. Very often, the whole focus is on memory problems. But distinguishing between what is healthy ageing memory and what are healthy ageing memory problems, as well as the problems associated with Alzheimer's disease (is challenging or problematic). With older people aged 85-plus, the region in our brain responsible for memory, or episodic memory, really atrophies or shrinks... their memory deficits might be due to normal ageing or Alzheimer's disease."*

### Lack of consensus on the signs and symptoms of Alzheimer's disease

Understandably, given the challenges, the panel believe experts are failing to agree on the signs and symptoms that constitute early signs of Alzheimer's disease. *"We tend to focus on memory loss but in fact, there's a whole slew of other symptoms that can be seen in early stages that can either help or complicate the picture,"* says Schall. *"Putting memory loss aside, there is agitation, constant pacing, sometimes behaviour that has turned aggressive, hallucinations, delusions, paranoia, the type of symptoms that people tend to think as coming later in the dementia process, but it's not necessarily the case. These neuropsychiatric symptoms can be evident in early dementia as well, so that complicates the difficult question around consensus."*

According to Barbarino, another complicating factor is that dementia is just a broad term given to describe some 104 conditions affecting the brain—with Alzheimer's disease being the most common—making the development of patient pathways enormously complex. She says: *"But because there is no consensus, we need to read waves of literature to get to the minimum common denominator of where evidence-based science is in agreement on some factors."* Nonetheless, she adds, patient advocacy groups should not be deterred from the *"incredibly challenging ambition"* of building a consensus and using it to gain traction with governments to secure policy changes to improve timely diagnosis.

Hornberger also agrees. The aspiration of achieving some sort of consensus that lists the warning signs and classic mistakes that signal the development of Alzheimer's, such as putting things away in the wrong place or not emptying the dishwasher would be very helpful, he says. *"It may be really difficult but I think it is really critical to come up with a consensus."*

### The value of knowing earlier

The panellists concur on the positive value of a timely diagnosis of Alzheimer's disease.

Schall explains: *"Caregiver Action Network asked carers whether they thought their caregiving situation came upon them suddenly, or over time. And, interestingly, it was about 50-50. Even with Alzheimer's, which progresses somewhat slowly over the years, half of family caregivers and carers thought of it as something that happened all of a sudden."* From a carer's perspective, knowing early provides time to prepare the support needed by loved ones. There are benefits for patients, too: *"There may be some functional areas that your loved one with dementia cannot do as well but other functional areas where they're fine."* A more nuanced understanding of the disease could support a better planned and appropriate care journey, rather than moving straight to a nursing home as can be the case far too often in the United States, he adds.

For Barbarino, the key driver to convince people of the benefits of timely diagnosis of Alzheimer's disease and other dementias, will be when better diagnosis and treatments become available.

## How technology can help

According to Hornberger, innovations are being developed to help timely diagnosis of Alzheimer's disease in primary care.

### • Mobile-technological solutions:

Hornberger and his team are currently exploring ways to measure and track memory using mobile phones. Instead of the traditional school memory tests of learning and recall, scientists are developing more valid, real-world assessments that can work using mobile technology. Tests of these mobile-based solutions are being carried out in India: *"Mobile phones are ubiquitous in India, nearly everybody has a mobile smartphone, even though they might not have a computer. So we are exploring whether it is possible to do a cognitive assessment using mobile phones in that country. ... The great thing is technology lets you directly connect a person with their family or a healthcare provider, or paramedics, to check on their status and it's fairly cheap."* The low price tag should also mean that low-income countries will be able to access this emerging technology. In addition, says Hornberger, *"We're very interested in examining spatial disorientation, which we know might emerge already before memory symptoms... The tests for spatial disorientation are fairly straightforward to do and, if you can make them mobile based, fantastic, you can really reach many, many more people than ever."*

### • Artificial intelligence:

AI offers the potential for detecting Alzheimer's disease or other forms of dementia by analysing voice patterns over time. *"It's very exciting"*, says Hornberger, *"several companies are working on this right now."*

### • Blood tests:

The chemical diagnosis of Alzheimer's disease is made possible by detecting levels of toxic proteins (beta-amyloid and tau) which accumulate in the nerve cells of the brain in people with Alzheimer's. Although such tests have been available for some time, they have required a lumbar puncture (injection into the spine). According to Hornberger: *"The holy grail for the last 20 years has been to get a working blood test for Alzheimer's disease, because it's technologically very, very difficult. There have now been experimental studies on blood tests for Alzheimer's around the world .... we need to be, of course, very careful in how early we test people and what that means but, as a technology, I think it will be completely game-changing. And, actually, I think neuroimaging will become a thing which is only used for a very unusual diagnoses. I think the blood tests will become very, very big in that sense."* (For more see reference below<sup>5</sup>.)

### • Data integration:

Efficient algorithms for fast integration of patient data sets across different morbidities will provide further opportunities for a more timely diagnosis of Alzheimer's disease, given the fact that cardiovascular disease and type-2 diabetes are both major risk factors for dementia. Interrogating the data may identify patients at risk of developing dementia. Says Hornberger: *"We're still 'siloing' data collection of so many different diseases – it's a bugbear of mine... I think we could make a huge difference to risk reduction and treatment approaches in the future just by using a very simple technological approach to integrate those datasets."*

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5 <https://www.scientificamerican.com/article/detecting-alzheimers-gets-easier-with-a-simple-blood-test/>

On the question of timely diagnosis of Alzheimer's, a poll taken of webinar attendees found that as many as half were actively involved in discussions on the subject and if they were not actively pursuing discussions on this topic, a significant proportion are thinking about it – 29%.

#### Poll of the attendees of the webinar I

Carer/patient organisations participating in the webinar were asked:

**Is your patient/carers/advocacy group currently involved in discussion on timely diagnosis of Alzheimer's or dementia?**

N=17

Yes

50%

No

7%

We are thinking about it

29%

I do not know

14%

**If you answered 'yes', what action is your organisation taking to support timely diagnosis of Alzheimer's/dementia?** (Participants could select more than one option.)

N=17

Undertaking a review/research

33%

Raising public awareness

67%

Working closely with primary healthcare professionals

67%

Providing support to carers, family, friends

67%

Raising funds for developing new technology

17%

#### Message for carer and patient advocates in driving change

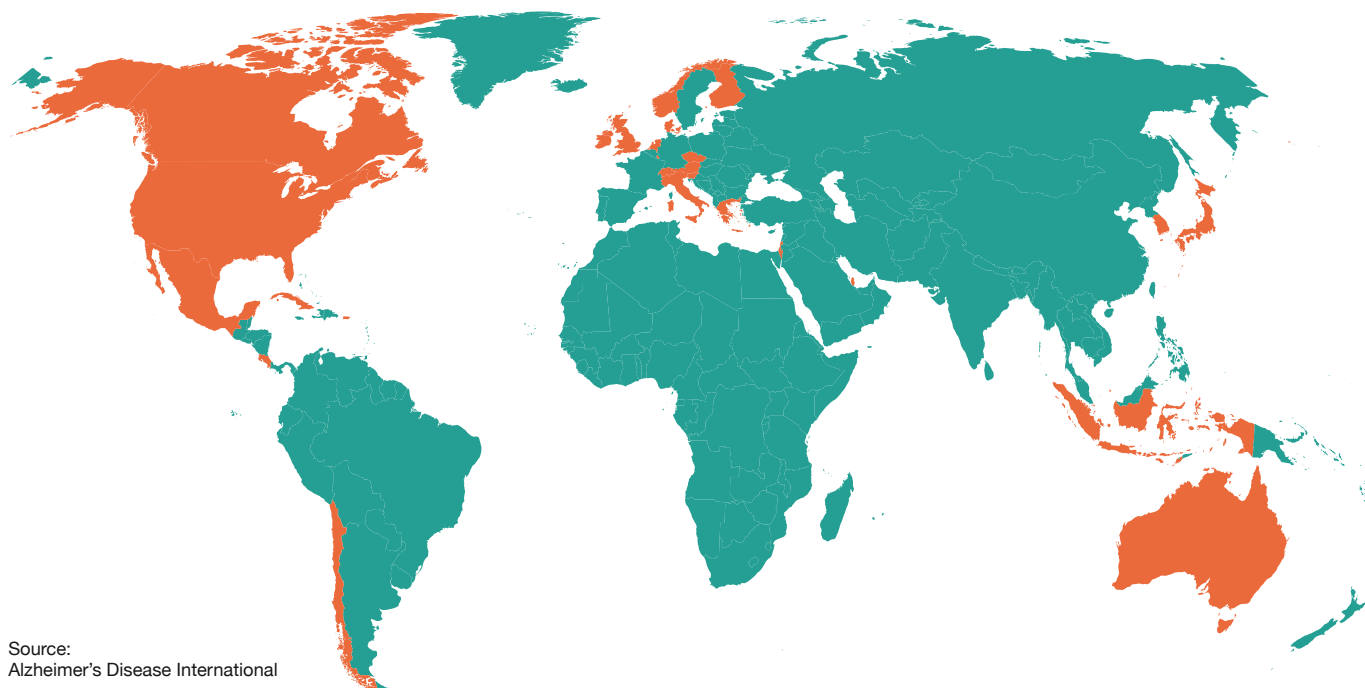
For Barbarino, all of the above is only made possible when there is appropriate investment and political will. Thus far civil society has been the major actor effecting change: *"The biggest enabler is the capacity of civil society to mobilise itself and, ultimately, politicians and policymakers to listen to the people that vote for them... We (patient advocacy groups) are at the central point between a scientific community that is doing fantastic work (and the public)... The challenge is to translate it and to get to implementation - to get governments to listen. That is extraordinarily challenging. The dementia movement is still trying hard to play catch-up with other disease areas that have won greater recognition and funding. Cancer and Alzheimer's were discovered pretty much at the same time, but the cancer movement organised itself much earlier in the 1930s. Alzheimer's organisations organised themselves much later, with Alzheimer's Disease International forming in the 1980s and that really tells you why we are so much behind."*

However, significant progress has been made. For example, Alzheimer's Disease International began to measure its influence by counting the number of interactions on social media during its awareness raising campaign, World Alzheimer's Month. In 2018, ADI achieved 900,000 interactions but this rose to 2 million the following year, and 20 million the year after and 45 million last year. *"The capacity for us to mobilise a movement is growing together with our members. And as the national and international movement has gotten stronger, our capacity to influence policymakers has too grown stronger. That is the biggest untapped enabler - making citizens aware that they can demand better... we are a lot of people. And together, we are certainly going to cope with it better and find better solutions,"* says Barbarino. A key measure of the impact of the third sector involved with dementia is the decision by the World Health Organization in 2017 to implement a global action plan for dementia. According to Barbarino, while

## Countries with a national dementia plan ■

Although a large number of countries appear to have adopted a dementia plan, *they are not always implemented*

Australia	Chile	Czech Republic	France	Ireland	Japan	Malta	Norway	Switzerland
Austria	Costa Rica	Denmark	Greece	Israel	South Korea	Mexico	Qatar	UK
Canada	Cuba	Finland	Indonesia	Italy	Luxembourg	Netherlands	Slovenia	USA



Source:  
Alzheimer's Disease International

many countries have incorporated this plan, they need to attract government funding to make a real difference for patients and family carers. Italy and Mexico, for example, have national plans for dementia but without funding, *“they are basically pretty pieces of paper”*, she says.

According to Barbarino, aside from persuading governments to adopt national policies on dementia, patient advocacy groups have also focused on Human Rights legislation. The World Health Organization points out that people living with dementia and their caregivers have the right to be free from discrimination based on any grounds such as age, disability, gender, race, sexual orientation, religious beliefs, health status, and also directly because of their dementia. The United Nations

also recognises dementia as a disability. In the context of this webinar, the stigmatisation that comes with dementia provides another significant impediment to those who should seek a diagnosis.

*“We are also trying,” says Porto, “to help with the Brazilian national politics, some health policies about dementia, and we are discussing how.”* Just like other patient advocacy groups, ABRAz is working hard to move dementia up the government’s priority list. *“I believe is very important, crucial to have a national plan on dementia. We are also providing psychoeducation to families, trying to reduce suffering in every state. We talk about dementia, we talk about behaviour problems, we talk about treatments, resources, how to view the future, what steps need*

## Poll of the attendees of the webinar II

Carer/patient organisations participating in the webinar were asked:

**How confident is your organisation about being able to influence government policymakers in order to improve timely diagnosis?**

N=17

Very confident

7%

Confident

67%

Not confident

7%

We are not in a position to effect change

13%

Do not know

7%

**How confident is your organisation about being able to influence healthcare professionals in order to improve timely diagnosis?**

N=17

Very confident

7%

Confident

57%

Not confident

14%

We are not in a position to effect change

14%

Do not know

7%

*progression,” says Porto. “For ABRAz and all third sector organisations it is important to improve the scenario. I always like to think that it would be a big mistake to do nothing. If you can do only a few small things, do the few things that you can do. The mistake would be to do nothing.”*

Because issues relating to Alzheimer's disease and other dementias are so complex, it is a constant challenge for NGOs working in this field to secure clear policy positions. Says Schall: *“We have to be very much on the alert for getting mixed signals from governments and policymakers. We have got to advocate for very clear policies. Using the US as an example, finally after 20 years, perhaps (we have) a therapy, that that may be useful in terms of amyloid and, in the US regulatory process the new therapy gets approved by the FDA. But the US Medicare program doesn't want to pay for it — giving very, very mixed signals. And those mixed signals can immediately strangle the feeling of ‘finally, we have some hope in this area’. So, it's very important for us as advocacy organisations...”*

Despite the considerable challenges in moving dementia funding up the policy agenda, charities and advocacy attract recognition for their work. According to Professor Hornberger, *“I think civil society do such incredible engagement and policy work, but I think we really need to mobilise much more. From an academic perspective, we're just working much closer with the Patient Advocacy Groups and charities. Together, I think this is really where we can hopefully push each other in a way to bring more kind of expertise to the table and support each other.”*



## Case study Dementia in Brazil

The scale of dementia (mainly Alzheimer's disease) has reached epidemic levels across the world, but in regions like Latin America the disease is set to rise exponentially. According to the World Health Organization 3.8 million people live with the condition in Latin America. By 2050, those numbers are set to rise by 363%.

Dr Fábio Porto, Scientific Director of Associação Brasileira de Alzheimer – ABRAZ in São Paulo, says the situation in Brazil is particularly worrying. There are 30 million elderly people in the country, 1.8 million of whom are currently estimated to have dementia—a figure, Porto says, is likely to be an under-estimation. By 2050, the official numbers of those with dementia is expected to reach 5.6 million.

As the chart below shows, as a low-to-middle income country, Brazil seems especially vulnerable. In 2020, an article in 'The Lancet' identified key risk factors associated with dementia<sup>1</sup>. Poor education

was named near the top of list. In 2019, 6.6% of the population in Brazil was found to be illiterate. According to Porto, it is therefore no surprise that most Brazilians have a poor understanding of the disease. *"In Brazil dementia is often seen as madness, craziness, a lack of control," he says. "A lot of patients, when they hear they have dementia, have this image of a patient in a bed not eating, not drinking with spasticity. And this is not the true. This is really a wrong idea, or wrong perception about dementia."*

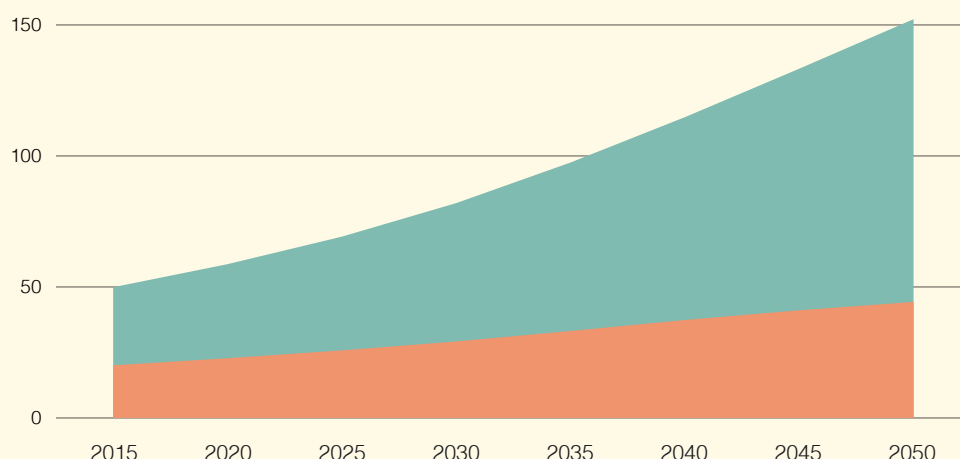
This cultural outlook has stigmatised those living with dementia and also explains why, according to a study by Universidade Federal de São Paulo, some 77% of Brazilians with dementia remain undiagnosed<sup>2</sup>—and why figures may be underreported. Says Porto, *"I see many families mis-believing that dementia is normal. My impression is that it's a kind of euphemism. They think 'if it's not (dementia) then I don't need to care. It's not a problem.' But this always makes the suffering*

### Global dementia is forecast to rise dramatically in low-income countries

Number of people with dementia (millions) in low and middle income countries compared to high income countries

High income countries  
Low and middle income countries

Source: World Health Organization



1 [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

2 [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(15\)60153-2/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(15)60153-2/fulltext)

*(eventually) greater. If you don't (accept) something is happening, you don't have time to prepare and you don't have access to treatments or psychoeducation to know how to deal with behaviour problems or how to deal with the memory and the other cognitive issues."*

### **The work of ABRAz to improve timely diagnosis**

Porto believes public and medical education should be a central strategy to improving dementia diagnosis and care in his country: *"I believe it's essential to explain what dementia is,"* he says. Poor education can affect diagnosis, he explains, *"Because you don't know if the patient can't remember due to poor education or because they have disease... Detecting the early signs of dementia is difficult for everybody but it is even more difficult for patients with a poor education. It's difficult to test memory language, attention, executive functions. So, something that we are trying to prove is that if you focus on functional abilities, it's easier for families to understand. For example the patient was able to do X but now he or she is not able to do it. This is something that's easier to explain, and it's easier for families to note. Evaluating the functional capacity in real life, what kind of activities was the patient able to do and is no longer able to do anymore, is easier."* The patient group also operates training and support programmes for the public at a regional level in the country, and uses these forums to try to improve care by talking about dementia, its related behaviour problems, treatments, resources and how to view the future.

ABRAZ also focuses on healthcare professionals since, says Porto: *"limited knowledge also occurs in the healthcare sector, mainly primary care. Doctors in Brazil are not used to diagnosing, they don't have access mainly to imaging, MRI, CT, or more advanced neuroimaging like PET scans, and they are not*

*practiced in doing cognitive screening, so if they are not used to it, they don't know how to do it, they will not do it in the practice."* The patient organisation thus provides medical education for primary care physicians, hosting a free (annual) congress on geriatric neuropsychiatry. *"We always try to have at least one part on improving diagnosis in primary care, so trying to improve doctors' ability to talk about dementia."*

### **Public health policies and healthcare infrastructure**

When compared to high income countries, Brazil compares unfavourably in terms of public health measures aimed at reducing the other risk-factors associated with dementia—as identified in 'The Lancet' article, namely hearing loss, traumatic brain injury (TBI), hypertension, alcohol consumption, and obesity. As Porto notes, *"these are problems all around the world but, here in Brazil there are no adequate public health policies and resources to enable early intervention and prevention"*.

Porto adds *"It is the same situation for health policies regarding access to healthcare for the elderly. We have difficulty in diagnosing memory problems or memory complaints. We have difficulty in treating depression, or (carrying out) mood evaluation or (making a) good diagnosis. We don't have public programmes to increase social contacts, cognitive rehabilitation, so there are problems that are structural, here in Brazil, but, also in other Latin American in low-income countries....Brazil lacks memory clinics - these are restricted to universities – so there are few places where you can get a clear diagnosis, and where doctors and healthcare providers have the knowledge to talk about dementia and diagnose it. The country also lacks a national dementia plan."*



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## Executive summary and takeaway messages

Dementia (including Alzheimer's disease) is rapidly increasing in prevalence worldwide, yet governments and healthcare systems are failing to provide the resources and investment to tackle this universal medical problem – whether in high, medium, or low-income countries.

PatientView, with sponsorship from Novo Nordisk, decided to explore the factors that prevent timely diagnosis and what could enable it, by holding an international interactive webinar on February 21st 2022.

PatientView is a company with over 20 years' experience of collating and disseminating the opinions of all patient organisations, including those dealing with Alzheimer's disease and dementia. Novo Nordisk has a specific interest in the topic as it has a potential Alzheimer's disease treatment in clinical study.

The webinar brought together four panellists with very different perspectives of Alzheimer's disease:

- **Paola Barbarino**, Chief Executive Officer, Alzheimer's Disease International (ADI).
- **Michael Hornberger**, Professor of Applied Dementia Research, at Norwich Medical School, UK.
- **Dr Fábio Porto**, Scientific Director of Associação Brasileira de Alzheimer (ABRAz), São Paulo, Brazil and Neurologist
- **John Schall**, CEO of Caregiver Action Network, USA.

They were joined by 17 representatives of carer/patient advocacy groups from 10 different countries. There was agreement across the group, as to the positive value and importance of a timely diagnosis of Alzheimer's disease. Although the group also recognised the many specific barriers that stand in the way. Together they also shared views on the actions needed to address these barriers.

### Barriers to timely diagnosis

Their discussion covered the many barriers that stand in the way of a timely diagnosis of Alzheimer's disease, for example:

- how in primary care the condition is often confused with normal ageing
- the lack of agreement on the symptoms that constitute early onset of Alzheimer's disease
- the challenge of helping the public recognise the importance of getting a diagnosis.

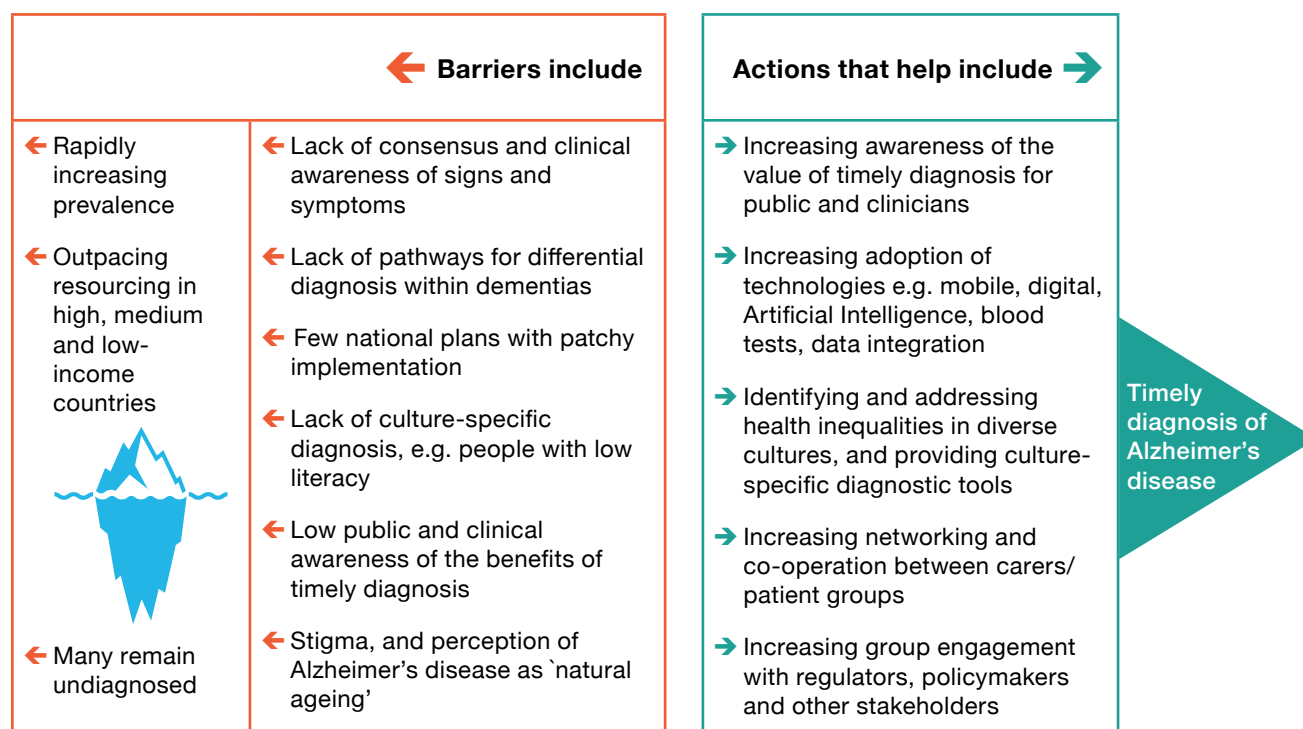
## Focusing on actions that could promote timely diagnosis

The panellists identified priorities for action:

- ➔ **Education** Dr Fábio Porto, in particular, emphasised the need for more education not only of the public, but healthcare professionals, who have many misconceptions about Alzheimer's disease, which in turn discourage the implementation of timely diagnosis. Alzheimer's Disease International (ADI) found that 62% of healthcare professionals who responded to a survey for the 'World Alzheimer Report 2019: Attitudes to dementia' believed that dementia is a part of normal ageing, and is not a disease. John Schall pointed out that research undertaken by Caregiver Action Network, found that as many as half of the carers they surveyed believe that 'full-blown' dementia occurs speedily, which is not the case.
- ➔ **Promotion of new technologies.** Professor Michael Hornberger outlined how many new technologies are emerging to facilitate the diagnosis of Alzheimer's disease, which to-date largely depends on (sometimes unreliable) memory tests,

### Overall objective:

Identify how timely diagnosis can be achieved, and how patient groups can support this goal



Source: PatientView, 2022

and neuroimaging, when available. According to Hornberger, there may be other simpler and more accessible methods to detect Alzheimer's disease in its early stages, such as digital tools to help measure spatial awareness. However, he added, in parallel, the major breakthrough will also continue to be blood tests for Alzheimer's disease once they become more widely available.

→ **Tackling health inequities.** Providing a case study from his homeland, Brazil, Porto talked about the difficulties using memory tests for Alzheimer's disease, in a culture where there are low levels of literacy. Instead, ABRAz is investigating alternative diagnostic clues of Alzheimer's disease, which are more meaningful to affected families, such as focusing on a person's functional abilities.

→ **Greater networking between carers/patient groups.** Paola Barbarino described how civil society has had a significant impact on policymaking, ensuring recognition that dementia is a key national priority, and highlighted the need for greater co-operation between groups. Hornberger, acknowledged the potency of civil society, but felt there was potential for greater mobilisation through increased networking.

→ **Greater patient group engagement with other healthcare stakeholders.** Hornberger added that he saw such networking being valuable across all healthcare stakeholders including academics like himself: *"Together, I think this is really where we can hopefully push each other in a way to bring more kind of expertise to the table and support each other."*

Paolo Barbarino, Chief Executive Officer, Alzheimer's Disease International (ADI), provided a final takeaway message of the February 21st 2022 webinar:

*"Globally ageing populations, COVID-19, plus diagnostic and treatment breakthroughs will create a tsunami of demand for health systems, which are woefully unprepared. Through implementing funded national dementia plans, governments can better prepare and potentially avert this impending crisis. As a community, we have the power to hold our governments accountable and ensure they follow through with their previous promises to improve the lives of those living with dementia and carers."*

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## Appendix

### **PatientView/Novo Nordisk November 2021 pilot survey on the challenges resulting in achieving a timely diagnosis of Alzheimer's disease**

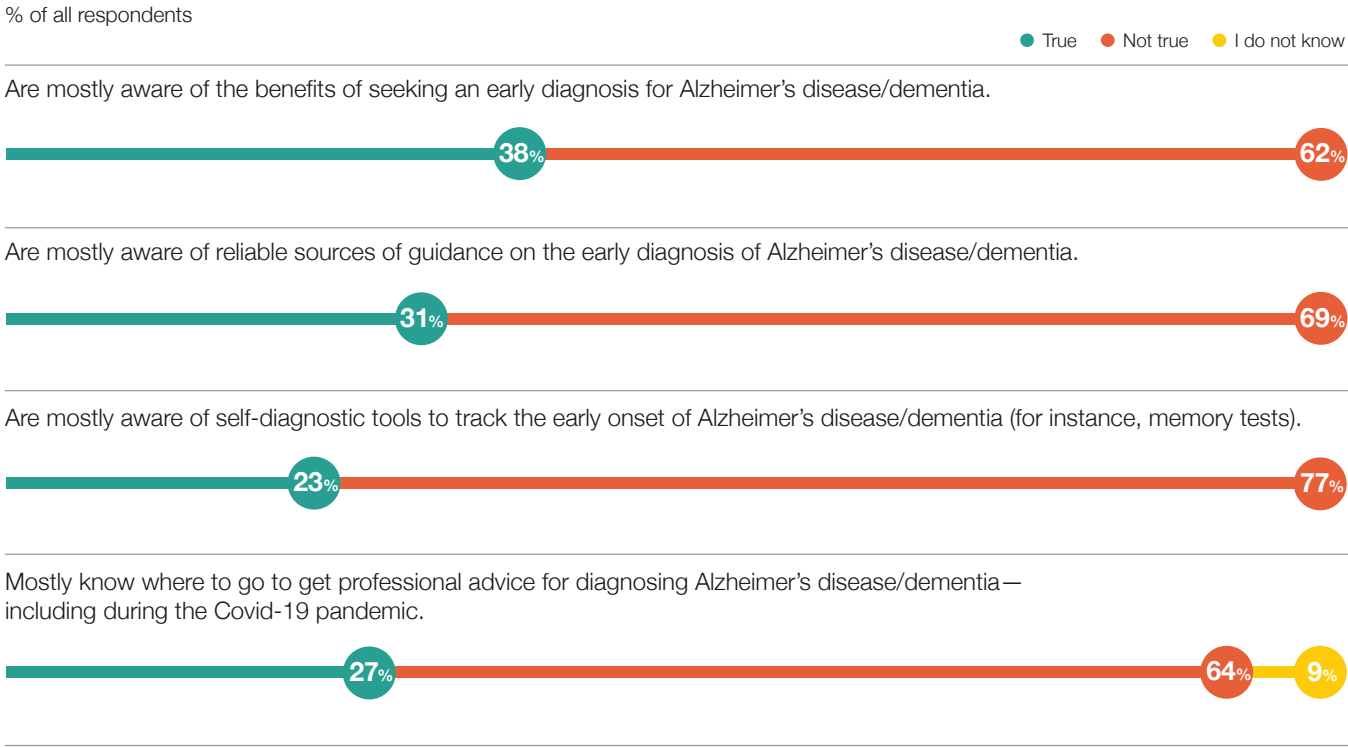
To inform the agenda for the webinar of February 21st 2022, PatientView conducted a small survey of 13 patient/carers groups from Bulgaria, Canada, France, India, Italy, Spain, UK and Zimbabwe. All had experience of dementia and/or Alzheimer's disease. These patient groups were asked several questions on the challenges

faced in obtaining a timely diagnosis of Alzheimer's disease, and were asked to provide commentaries to explain their answers. The results of this survey were presented at the webinar.

Quantitative and qualitative results are shown in the next few pages.

Quantitative feedback from respondents to PatientView/Novo Nordisk mini-survey (4 questions)

Q1: Which of the following statements are “True” or “NOT true” in your country (or your part of the country)?  
Members of the public ...



**Q2:** In your country (or your part of the country), which of the following statements are "True" or "NOT true" (or "It depends on the GP")?

**The general practitioner (GP)/family doctor, or nurse ...**

% of all respondents

● True ● Not true ● It depends on the GP ● I do not know

Is the first place that members of the public/patients (or their carers) turn to discuss their concerns about Alzheimer's disease/dementia.



Routinely includes 'brain health' and memory as part of regular age-related health check ups.



Routinely includes 'brain health' and memory as part of regular health check ups for patients perceived as being at higher risk of dementia.



Before the time of Covid-19: usually agrees to requests from members of the public/patients (or their carers) for a face-to-face examination on the early signs of Alzheimer's disease/dementia.



During the time of Covid-19: usually agrees to requests from members of the public/patients (or their carers) for a face-to-face examination on the early signs of Alzheimer's disease/dementia.



**Q3:** In your country (or your part of the country), which of the following statements are "True" or "NOT true" (or "It depends on the GP")?

**The general practitioner (GP)/family doctor, or nurse ...**

% of all respondents

● True ● Not true ● It depends on the GP ● I do not know

Generally recognises the importance of early diagnosis of Alzheimer's disease/dementia.



Is generally knowledgeable about the procedures necessary for diagnosing Alzheimer's disease/dementia.



Communicates clearly to the person concerned/patient (or their carers) the steps required for early diagnosis of Alzheimer's disease/dementia.



Involves the person concerned/patient (or their carers) in making decisions about the planning of early-diagnostic steps for Alzheimer's disease/dementia.



Usually encourages members of the public/patients to undergo an examination for early diagnosis of Alzheimer's disease/dementia, if they (or their carers) request this.



Usually discourages members of the public/ patients (or their carers) from undergoing an examination for early diagnosis of Alzheimer's disease/dementia, even if they request this.



**Q4: In your country (or your part of the country), HOW GOOD are general practitioners (GPs)/family doctors, or primary-care nurses, at performing the following activities relevant to early diagnosis of Alzheimer's disease/dementia?**

% of all respondents

	Very good.	Good.	Fair.	Poor.	It depends on the GP.	I do not know.
Conducting relevant cognitive and memory tests.	0%	0%	15%	23%	54%	8%
Considering the needs of diverse patients.	0%	0%	15%	23%	46%	15%
Considering factors that could bias results.	0%	0%	0%	23%	69%	8%
Conducting tests to eliminate other potential causes of symptoms.	0%	15%	0%	23%	54%	8%
Referring patients to specialist teams for further diagnosis.	15%	15%	15%	15%	38%	0%
Coordinating with all specialists involved in the diagnosis.	0%	15%	15%	31%	31%	8%
Providing patients/carers with constant access to their medical records.	0%	15%	15%	31%	38%	0%
Communicating clearly the implications of test results.	0%	15%	8%	31%	46%	0%
Providing a definitive diagnosis—eg., of Alzheimer's disease.	0%	8%	15%	38%	38%	0%
Addressing the fears that patients/carers may have.	0%	0%	31%	23%	38%	8%



## Commentaries from respondents to PatientView/Novo Nordisk mini-survey (5 questions)

The 16 key challenges raised by the 13 respondents across all five qualitative questions in the survey

Rank	Category	# of mentions*
1	Difficult to find primary carers who will help	23
2	Lack of capacity for diagnosis	15
3	Lack of effective strategy and pathways	13
4	Need for public education	11
4	Need for clinician training	10
6	Fear (e.g. loss of independence)	6
6	Stigma	6
8	No benefit of diagnosis (e.g. lack of effective treatment)	5
8	Public/family/GP belief disease is natural ageing	5
8	Lack of integrated care	5
11	Patient resists or denies diagnosis	4
11	Need to co-ordinate with patient groups	4
13	Clinician focuses on other symptoms easier to treat	2
13	Need for early diagnostic tools	2
13	Poor co-ordination between multidisciplinary team	2
13	Poor continuity of care	2

\* In some cases a respondent may have repeated the point in multiple questions. Some comments may be included in more than one category.

Challenge:	Difficult to find primary carers who will help
<p><i>Number of mentions across survey = 23</i></p>	<p>"To have an understanding doctor." <b>Local Alzheimer's patient group, France</b></p> <p>"While the statements above are about GPs in general, there are some GPs who do well with dementia care. Some practitioners of family medicine refer patients early for diagnosis and treatment." <b>Regional dementia/older people patient group, India</b></p> <p>"Therapeutic nihilism about dementia exists among many GPs. They advise the families not to provide any treatment." <b>Regional dementia/older people patient group, India</b></p> <p>"Accessing right people for advice and help; cost of investigations." <b>Regional dementia/older people patient group, India</b></p> <p>"In India, the primary care system in health is not very well established. Many families seek direct help from specialists instead of approaching their family doctors." <b>Regional dementia/older people patient group, India</b></p> <p>"Depending on the GP, the normal situation in this stage of the system, is not to seek dementia in the patients...." <b>National dementia/Alzheimer's patient group, Spain</b></p> <p>"Getting access to a face-to-face appointment to a GP is practicably impossible in my part of the country. GPs need to be made aware of the importance of early diagnosis for any illness." <b>Local carers' support group, UK</b></p> <p>"...if you don't keep worrying the GP you will not get what is needed for an early diagnosis." <b>Local carers' support group, UK</b></p> <p>"Having had experience of, and losing my wife to dementia, I fought long and hard for my wife to be referred to the memory clinic to get a diagnosis. Following the diagnosis I was then able to access other forms of support. But it was hard work and very time consuming." <b>Local carers' support group, UK</b></p> <p>"Difficult to get appointments. GP awareness and understanding..." <b>Local dementia patient group, UK</b></p> <p>"...GPs don't understand why we need early diagnosis so don't encourage people to come forward with their concerns." <b>Local dementia patient group, UK</b></p> <p>"There is an initial triage system which may result in a telephone follow-up rather than a face-to-face meeting. Elderly patients struggle with accessing the online appointment system and if they phone may give up if they do not receive an immediate response and then enter a queue or if they have to make choices about choosing different options. Patients are not allowed to present in person at the surgery to book an appointment." <b>Local carer/dementia patient group, UK</b></p> <p>"People may know where to go to start this journey but regularly face barriers in accessing an initial GP appointment and then a referral for a detailed assessment via the Memory services..." <b>Local carer/dementia patient group, UK</b></p> <p>"The key challenges include getting that initial assessment...accessing a GP with an interest in dementia..." <b>Local carer/dementia patient group, UK</b></p> <p>"Other clients have been fobbed off and not immediately referred for further assessment so diagnosis has been delayed. A number of clients who use our services and who clearly have cognitive impairment have no formal diagnosis as yet." <b>Local carer/dementia patient group, UK</b></p> <p>"Some clients have reported helpful encounters with their GP and have felt listened to, and then referred for more detailed assessment at the Memory Clinic." <b>Local carer/dementia patient group, UK</b></p> <p>"Not getting an appointment to see a GP..." <b>Local older people's patient group, UK</b></p> <p>"GP undergoing basic physical checks for infection rather than simply referring to memory clinic...." <b>Local older people's patient group, UK</b></p> <p>"Key challenge is getting a GP who has expertise in care of the elderly - often local practices have revolving doors of locums." <b>Local older people's patient group, UK</b></p> <p>"Access to a health facility and costs" <b>National dementia patient group, Zimbabwe</b></p> <p>"With some practitioners the outcome is positive and will refer the patient to a specialist for further investigation having done other tests to see if there are other reasons for symptoms of memory loss etc" <b>National dementia patient group, Zimbabwe</b></p>

"Many patients are sent away being told that it is just a natural part of aging and that there is nothing that can be done."

**National dementia patient group, Zimbabwe**

"One of the key challenges is finding the right practitioner and not being afraid to ask for a 2nd opinion. Some GPs have more interest and understanding of dementia than others."

**National dementia patient group, Zimbabwe**

Challenge:	Lack of capacity for diagnosis	
<i>Number of mentions across survey = 15</i>	<p>"There isn't a National Plan for Dementia in Bulgaria. Problem with finance."</p> <p><b>National carer/dementia patient group, Canada</b></p> <p>"1. Education 2. Finance 3. National health policy for people with dementia and support for their relatives and informal caregivers."</p> <p><b>National carer/dementia patient group, Canada</b></p> <p>"...The training for regular carers does not include knowledge and skills for working with people with dementia. Furthermore, no university in the country offers a study program in gerontology for a medical doctor."</p> <p><b>National carer/dementia patient group, Canada</b></p> <p>"In India, the primary care system in health is not very well established. Many families seek direct help from specialists instead of approaching their family doctors."</p> <p><b>Regional dementia/older people patient group, India</b></p> <p>"Accessing right people for advice and help; cost of investigations."</p> <p><b>Regional dementia/older people patient group, India</b></p> <p>"Covid-19 pandemic has altered the process of getting an early diagnosis in a specific time: the lock down. In these specific months the cure had priority on prevention."</p> <p><b>Regional dementia patient group, Italy</b></p> <p>"...Accelerate the referral of patients with dementia to specialized care services to obtain an accurate diagnosis as soon as possible, as well as improve coordination between these levels and reduce times between consultations."</p> <p><b>National dementia/Alzheimer's patient group, Spain</b></p> <p>"...not using the third sector as support for people to attend a diagnosis."</p> <p><b>Local carers' support group, UK</b></p>	<p>"Having had experience of, and losing my wife to Dementia, I fought long and hard for my wife to be referred to the memory clinic to get a diagnosis. Following the diagnosis I was then able to access other forms of support. But it was hard work and very time consuming."</p> <p><b>Local carers' support group, UK</b></p> <p>"A system for easy referral to memory clinic, if positive, then to a specialist for a definitive diagnosis."</p> <p><b>Local carers' support group, UK</b></p> <p>"Other clients have been fobbed off and not immediately referred for further assessment so diagnosis has been delayed. A number of clients who use our services and who clearly have cognitive impairment have no formal diagnosis as yet."</p> <p><b>Local carer/dementia patient group, UK</b></p> <p>"1. Routine assessment of older patients. 2. Expanded provision of Memory services and associated diagnostic tests. 3. Government drive to ensure GP services view this as a priority."</p> <p><b>Local carer/dementia patient group, UK</b></p> <p>"...There is limited capacity in the Memory services and families may not gain a full assessment until the individual is significantly compromised..."</p> <p><b>Local carer/dementia patient group, UK</b></p> <p>"GP undergoing basic physical checks for infection rather than simply referring to memory clinic - supporting people to do things which help them retain independence and making referrals to us for practical help."</p> <p><b>Local older people's patient group, UK</b></p> <p>"...Better, more affordable access to medical treatments for all the population."</p> <p><b>National dementia patient group, Zimbabwe</b></p>

Challenge:	Lack of effective strategy and pathways	
Number of mentions across survey = 13	<p>"National health policy for people with dementia and support for their relatives and informal caregivers." <b>National carer/dementia patient group, Canada</b></p> <p>"There isn't a National Plan for Dementia in Bulgaria. Problem with finance." <b>National carer/dementia patient group, Canada</b></p> <p>"...Having a national dementia strategy to facilitate policies that are dementia friendly." <b>Regional dementia/older people patient group, India</b></p> <p>"In India, the primary care system in health is not very well established...." <b>Regional dementia/older people patient group, India</b></p> <p>"...improve coordination between these levels [primary and specialized services] and reduce times between consultations." <b>National dementia/Alzheimer's patient group, Spain</b></p> <p>"A system for easy referral to memory clinic, if positive, then to a specialist for a definitive diagnosis." <b>Local carers' support group, UK</b></p> <p>"Time and money to provide such a service..." <b>Local carers' support group, UK</b></p> <p>"The system is not geared to early diagnosis..." <b>Local carers' support group, UK</b></p>	<p>"...I fought long and hard for my wife to be referred to the memory clinic to get a diagnosis. Following the diagnosis I was then able to access other forms of support. But it was hard work and very time consuming." <b>Local carers' support group, UK</b></p> <p>"1. Routine assessment of older patients. 2. Expanded provision of Memory services and associated diagnostic tests. 3. Government drive to ensure GP services view this as a priority." <b>Local carer/dementia patient group, UK</b></p> <p>"The key challenges include getting that initial assessment, having sufficient time to be able to talk through all concerns..." <b>Local carer/dementia patient group, UK</b></p> <p>"...A number of clients who use our services and who clearly have cognitive impairment have no formal diagnosis as yet." <b>Local carer/dementia patient group, UK</b></p> <p>"Many patients are sent away being told that it is just a natural part of aging and that there is nothing that can be done." <b>National dementia patient group, Zimbabwe</b></p>
Challenge:	Need for public education	
Number of mentions across survey = 11	<p>"...Education ...." <b>National carer/dementia patient group, Canada</b></p> <p>"Raise awareness among general public about how dementia is different from normal ageing, the importance of early diagnosis and benefits of treatment. ..." <b>Regional dementia/older people patient group, India</b></p> <p>"Lack of awareness about dementia. Many assume the changes in dementia to be part of normal ageing. This prevents them from seeking help early." <b>Regional dementia/older people patient group, India</b></p> <p>"...Achieve awareness in the family about the importance of detecting the first symptoms and quickly go to the doctor." <b>National dementia/Alzheimer's patient group, Spain</b></p>	<p>"It's important to provide the public information and education about the first symptoms of the disease, so they can go to GP seeking for early diagnosis, fighting against the actual consideration by the family that those symptoms are due to their age. ..." <b>National dementia/Alzheimer's patient group, Spain</b></p> <p>"Local authorities and GPs should provide a service via their Social Services and Surgery Depts. that can deal with making referrals for an early diagnosis. Also of making people aware of such a service." <b>Local carers' support group, UK</b></p> <p>"...General information available." <b>Local dementia patient group, UK</b></p> <p>"...General lack of information." <b>Local dementia patient group, UK</b></p>

"...receiving supportive and helpful information about where to get support and advice."

**Local carer/dementia patient group, UK**

"Awareness and education. "

**National dementia patient group, Zimbabwe**

"For patients - fear and acceptance. This is potentially life changing in that one loses 'adult rights'. For families - hysteria about what dementia is like - abundant scare stories."

**Local older people's patient group, UK**

## Challenge:

## Need for clinical training

Number of mentions across survey = 10

"There is a serious lack of trained specialists and staff at all levels — doctors, nurses, carers and social specialists. The list of official professions in Bulgaria does not include carers for people with dementia. The training for regular carers does not include knowledge and skills for working with people with dementia. Furthermore, no university in the country offers a study program in Gerontology for Medical Doctor."

**National carer/dementia patient group, Canada**

"...Sensitizing the physicians (GPs & family physicians) on early diagnosis & treatment for dementia."

**Regional dementia/older people patient group, India**

"Fight against stigma to all population, awareness. Active involvement of the GP through information. Multidisciplinary team in the diagnosis path."

**National dementia patient group, Italy**

"...Achieve awareness at the primary care level to quickly detect symptoms that may make suspect the onset of dementia; and provide them with the precise diagnostic tools ...."

**National dementia/Alzheimer's patient group, Spain**

"...is necessary raise awareness between GPs about the importance of considering those symptoms, and give the tools for a pre-diagnosis, and a rapid derivation to neurology area in order to confirm (or not) the right diagnosis."

**National dementia/Alzheimer's patient group, Spain**

"...GPs need to be made aware of the importance of early diagnosis for any illness."

**Local carers' support group, UK**

"GP awareness and training."

**Local dementia patient group, UK**

"GP awareness and understanding. "

**Local dementia patient group, UK**

"GPs don't understand why we need early diagnosis so don't encourage people to come forward with their concerns."

**Local dementia patient group, UK**

"Key challenge is getting a GP who has expertise in care of the elderly - often local practices have revolving doors of locums."

**Local older people's patient group, UK**

## Challenge:

## Fear (e.g. loss of independence)

Number of mentions across survey = 6

"Embarrassment. Anxious."

**Local Alzheimer's patient group, France**

"...worried that life will change ie driving license will be taken away so they tend to put it off."

**Local dementia patient group, UK**

"...Some individuals are reluctant to seek an assessment and diagnosis because of the implications of the diagnosis."

**Local carer/dementia patient group, UK**

"For patients - fear and acceptance. This is potentially life changing in that one loses 'adult rights'. ..."

**Local older people's patient group, UK** " ...being referred to memory clinic because one's children have decided that one has dementia (even though the older person was simply being private about his affairs)."

**Local older people's patient group, UK**

"...People quickly move from the status of wife, parent to being someone who is 'cared for'."

**Local older people's patient group, UK**

Challenge:	Stigma	
<i>Number of mentions across survey = 6</i>	<p>Embarrassment. Anxious.” <b>Local Alzheimer's patient group, France</b></p> <p>“Fight against stigma to all population, awareness.” <b>National dementia patient group, Italy</b></p> <p>“Stigma about the condition ....” <b>Local dementia patient group, UK</b></p>	<p>“Stigma about dementia...” <b>Local dementia patient group, UK</b></p> <p>“For patients - fear and acceptance. This is potentially life changing in that one loses “adult rights”. For families - hysteria about what dementia is like - abundant scare stories.” <b>Local older people's patient group, UK</b></p> <p>“Stigma reduction.” <b>National dementia patient group, Zimbabwe</b></p>
Challenge:	No benefit of diagnosis (e.g. lack of effective treatment)	
<i>Number of mentions across survey = 5</i>	<p>“Raise awareness among general public about ...benefits of treatment.” <b>Regional dementia/older people patient group, India</b></p> <p>“Therapeutic nihilism about dementia exists among many GPs. They advise the families not to provide any treatment.” <b>Regional dementia/older people patient group, India</b></p> <p>“Clear benefit to patient e.g. good social care support, treatment.” <b>Local older people's patient group, UK</b></p>	<p>“GPs don't understand why we need early diagnosis so don't encourage people to come forward with their concerns. General lack of information.” <b>Local dementia patient group, UK</b></p> <p>“Frequently cited disincentive to diagnosis is no benefit to patient ...” <b>Local older people's patient group, UK</b></p>
Challenge:	Public/family/GP belief disease is natural ageing	
<i>Number of mentions across survey = 5</i>	<p>“Raise awareness among general public about how dementia is different from normal ageing....” <b>Regional dementia/older people patient group, India</b></p> <p>“...Many assume the changes in dementia to be part of normal ageing. This prevents them from seeking help early.” <b>Regional dementia/older people patient group, India</b></p> <p>“...families are reluctant to go to GP to talk about some symptoms they think are because of age....” <b>National dementia/Alzheimer's patient group, Spain</b></p>	<p>“...fighting against the actual consideration by the family that those symptoms are due to their age...” <b>National dementia/Alzheimer's patient group, Spain</b></p> <p>“Many patients are sent away being told that it is just a natural part of aging and that there is nothing that can be done.” <b>National dementia patient group, Zimbabwe</b></p>

<b>Challenge:</b>	<b>Lack of integrated care (including social care)</b>	
<i>Number of mentions across survey = 5</i>	<p>"Continuity between assistant social and patient." <b>Local Alzheimer's patient group, France</b></p> <p>"Follow up and help from assistant socials." <b>Local Alzheimer's patient group, France</b></p> <p>"Local authorities and GPs should provide a service via their Social Services and Surgery Depts. that can deal with making referrals for an early diagnosis. Also of making people aware of such a service." <b>Local carers' support group, UK</b></p>	<p>"...Clear benefit to patient e.g. good social care support, treatment." <b>Local older people's patient group, UK</b></p> <p>"...A frequently cited disincentive to diagnosis is no benefit to patient and loss of privileges (e.g. driving licence, independence)..." <b>Local older people's patient group, UK</b></p>
<b>Challenge:</b>	<b>Patient resists or denies diagnosis</b>	
<i>Number of mentions across survey = 4</i>	<p>"Not wanting to accept what is happening." <b>Local Alzheimer's patient group, France</b></p> <p>"Some individuals are reluctant to seek an assessment and diagnosis because of the implications of the diagnosis." <b>Local carer/dementia patient group, UK</b></p>	<p>"...they tend to put it off." <b>Local dementia patient group, UK</b></p> <p>"...A frequently cited disincentive to diagnosis is no benefit to patient and loss of privileges (e.g. driving licence, independence)..." <b>Local older people's patient group, UK</b></p>
<b>Challenge:</b>	<b>Need to co-ordinate with patient groups</b>	
<i>Number of mentions across survey = 4</i>	<p>"Prevention screening from local associations, family doctor, specialist." <b>Regional dementia patient group, Italy</b></p> <p>"Public/patients (or their carers) need to have more communication with local associations" <b>Regional dementia patient group, Italy</b></p>	<p>"Need to more communication with local associations" <b>Regional dementia patient group, Italy</b></p> <p>"...supporting people to do things which help them retain independence and making referrals to us for practical help." <b>Local older people's patient group, UK</b></p>
<b>Challenge:</b>	<b>Clinician focuses on other symptoms easier to treat</b>	
<i>Number of mentions across survey = 2</i>	<p>"Depending on the GP, the normal situation in this stage of the system, is not to seek dementia in the patients, focus the attention in other diseases or age symptoms." <b>National dementia/Alzheimer's patient group, Spain</b></p>	<p>"GP undergoing basic physical checks for infection rather than simply referring to memory clinic." <b>Local older people's patient group, UK</b></p>

<b>Challenge:</b>	<b>Need for early diagnostic tools</b>	
<i>Number of mentions across survey = 2</i>	<p>"...provide them [GPs] with the precise diagnostic tools."</p> <p><b>National dementia/Alzheimer's patient group, Spain</b></p>	<p>"...give the tools for a pre-diagnosis, and a rapid derivation to neurology area in order to confirm (or not) the right diagnosis."</p> <p><b>National dementia/Alzheimer's patient group, Spain</b></p>
<b>Challenge:</b>	<b>Poor co-ordination between multidisciplinary teams</b>	
<i>Number of mentions across survey = 2</i>	<p>"Multidisciplinary team in the diagnosis path."</p> <p><b>National dementia patient group, Italy</b></p>	<p>"...improve coordination between these levels and reduce times between consultations."</p> <p><b>National dementia/Alzheimer's patient group, Spain</b></p>
<b>Challenge:</b>	<b>Poor continuity of care</b>	
<i>Number of mentions across survey = 2</i>	<p>"Continuity between assistant social and patient."</p> <p><b>Local Alzheimer's patient group, France</b></p>	<p>"Key challenge is getting a GP who has expertise in care of the elderly - often local practices have revolving doors of locums."</p> <p><b>Local older people's patient group, UK</b></p>



## Profiles of the 13 respondents

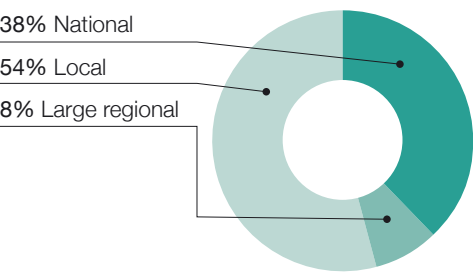
### Therapy areas



### Country headquarters



### Geographic reach



### Patient groups happy to be named

#### Bulgaria

→ Alzheimer Bulgaria Association

#### France

→ Alzheimer's Orne

#### India

→ Dementia Care in SCARF (DEMCARES)

#### Italy

→ AIMA – Associazione Italiana malattia di Alzheimer – NAPOLI APS

#### Spain

→ Confederación Española de Familiares de Enfermos de Alzheimer (CEAFA)  
→ Alzheimer León Spain

#### United Kingdom

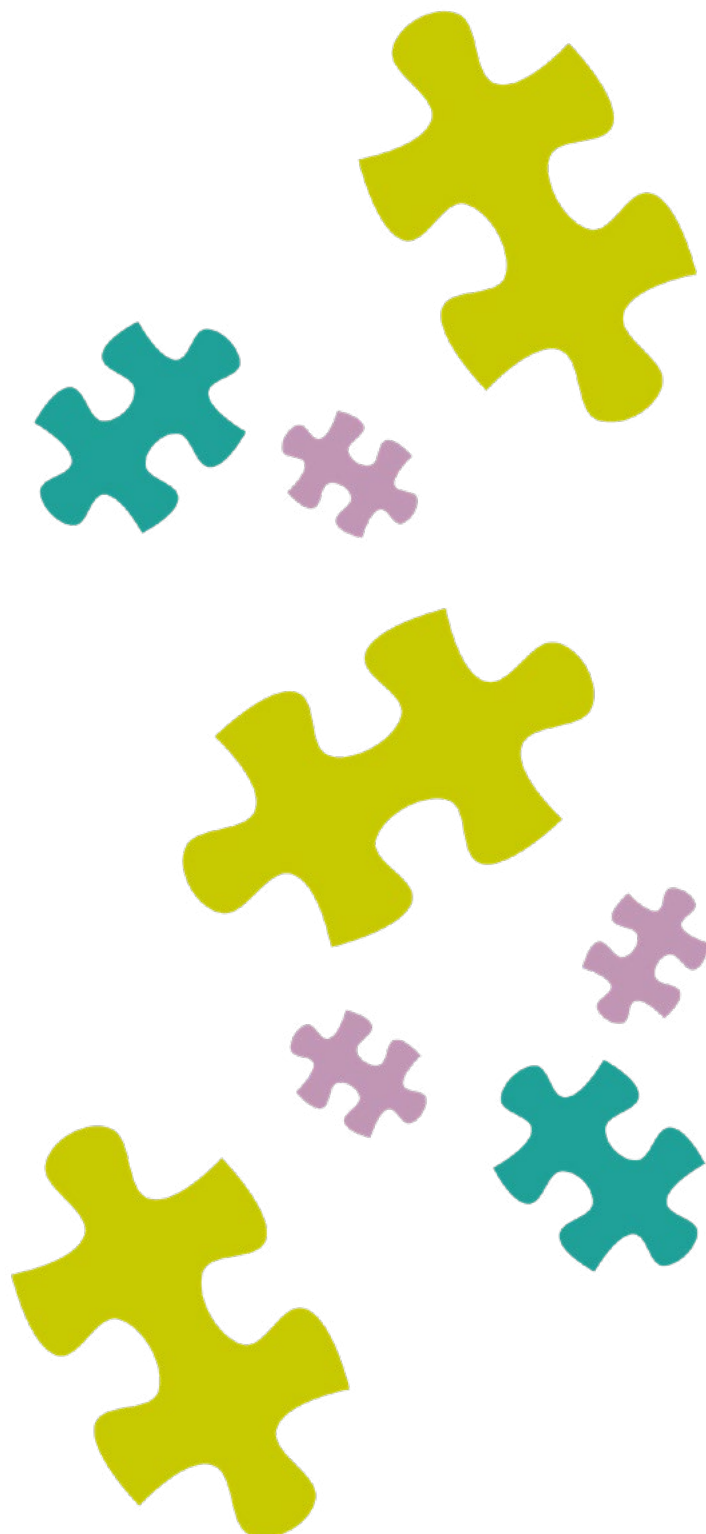
→ Age Concern Luton  
→ Dementia Friendly Hampshire  
→ West Lancs Peer Support

#### Zimbabwe

→ Zimbabwe Alzheimer's and Related Disorders Association—ZARDA

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PatientView/NovoNordisk would like to thank all the patient groups that contributed to the February 21st webinar on *the timely diagnosis of Alzheimer's disease*. We would also like to thank the panelists for all their time and input. We hope the webinar and this report make a valued contribution to this important subject.



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