NEW RESEARCH PUBLISHED:
TACKLING THE CHALLENGES OF GETTING A TIMELY
DIAGNOSIS FOR ALZHEIMER'S DISEASE

Identifying critical actions for patient groups

PRESS RELEASE
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London, May 4th 2022
As governments and healthcare systems grapple with the growing challenge of Alzheimer's disease and other dementias, a major stumbling block to improved health outcomes remains: getting a *timely diagnosis*. Timely diagnosis is critical to providing better Alzheimer's care. For this reason, PatientView, with sponsorship from Novo Nordisk, is pleased to publish today a report containing the results of new research, entitled: **'Tackling the challenges of getting a timely diagnosis for Alzheimer's disease'**.

The report and accompanying resources are being released into the public domain without copyright, to support patient-advocacy groups that have an interest in the field of Alzheimer's.
Download details can be found below.

PatientView is a research organisation with over 20 years of experience in collating and disseminating the opinions of patient organisations worldwide. Novo Nordisk, a leading global healthcare company headquartered in Denmark, has a specific interest in the topic of Alzheimer's, as it has a potential Alzheimer's-disease treatment in clinical study.

Continue reading for details on:

▸ The evidence base behind the new report;
▸ What carer/patient groups say about the challenges in getting a timely diagnosis of Alzheimer's disease;
▸ What healthcare experts say about possible solutions to the task of gaining a timely diagnosis of Alzheimer's disease;
▸ Signs of hope for the future; and
▸ Download details of the report, plus accompanying resources.

The evidence base

In keeping with the PatientView approach, the data collected for this new report relies heavily on patient input. The profiles of all contributors to the research on '*Timely diagnosis* of Alzheimer's disease' can be found in the main report. Two key sources inform the research results:

(1) In order to help define the **challenges that patients experience when they seek to obtain a timely diagnosis of Alzheimer's disease**, a survey was undertaken in October-November 2021 of a select number of carer/patient groups from different countries, each with experience of dementia and/or Alzheimer's disease.

(2) In order to identify **potential solutions to these challenges faced in obtaining a timely diagnosis**, a multi-stakeholder webinar was held in February 2022. Attending the webinar were representatives of carer/patient-advocacy groups drawn from around the world. Four experts, with different areas of expertise, headed up the 90-minute discussion:

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

What carer and patient groups say about the challenges faced in getting a timely diagnosis of Alzheimer's disease

The 13 carer and patient groups responding to PatientView's October-November 2021 Alzheimer's survey identified numerous challenges facing carers/patients who might want to gain a timely diagnosis of Alzheimer's disease [see diagram and table below].

These challenges can be categorised into four types of barriers, affecting …
(1) carers/patients; (2) health professionals; (3) healthcare systems; and (4) treatment and diagnosis.

Challenges in attaining a timely diagnosis of Alzheimer's disease, as identified by 13 carer/patient groups

Source: PatientView, 2022
Download:
https://bit.ly/3vpcIyn

PatientView, press release, May 2022

The 16 key challenges faced in getting a timely diagnosis of Alzheimer's disease
as identified by 13 carer/patient groups from eight different countries

Rank	Category	# of mentions*
1	Difficult to find primary carers willing to help	23
2	Lack of capacity for diagnosis	15
3	Lack of effective strategy and pathways	13
4	Need for public education on the subject	11
4	Need for clinician training on the subject	10
6	Fear among patients (for instance, of loss of independence)	6
6	The stigma of having dementia	6
8	No benefit to diagnosis (for instance, a lack of effective treatment)	5
8	Public/family/GP belief that the disease is just 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 that are easier to treat	2
13	Need for diagnostic tools	2
13	Poor co-ordination between multidisciplinary team	2
13	Poor continuity of care	2

* In some cases, a respondent carer/patient group may have repeated the same point in multiple questions. Some comments may be included in more than one category.

What healthcare experts say about possible solutions to the task of attaining a timely diagnosis of Alzheimer's disease
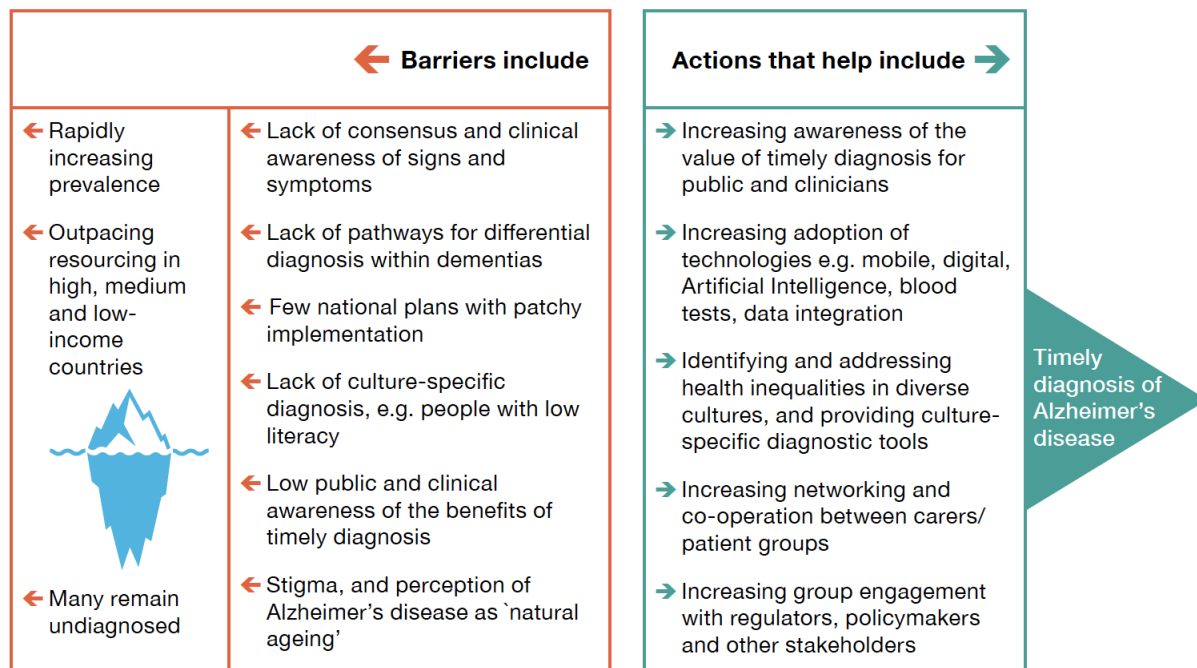
The four panellists at PatientView's February 2022 Alzheimer's webinar identified specific priorities for action that could go some way to addressing the challenges and barriers defined above—and, therefore, some way towards promoting *timely diagnosis* of Alzheimer's disease [see diagram below].

▶ **Education**. Dr. Fábio Porto, in particular, emphasised the need for more education on the subject of Alzheimer's—not only of the public, but also of healthcare professionals themselves. Both public and professionals retain many misconceptions about Alzheimer's disease—which, in turn, discourages the implementation of timely diagnosis.

▶ **Promotion of new technologies**. Professor Michael Hornberger described how new technologies are emerging to facilitate the diagnosis of Alzheimer's disease. To date, diagnosis has largely depended on sometimes-unreliable memory tests, and, when available, neuroimaging. The greatest diagnostic breakthrough will happen when blood tests for Alzheimer's disease—which currently exist now—become more-widely available.

▶ **Tackling health inequities**. Providing a case study from his homeland of Brazil, Dr. Porto talked about the difficulties that come with the use of memory tests to diagnose Alzheimer's disease in any national culture where levels of personal literacy are low. His patient group, ABRAz, is instead investigating alternative diagnostic clues to Alzheimer's disease, clues which might be more meaningful to affected families in low-literacy parts of the world.

PatientView, press release, May 2022

▶ **Greater networking across all healthcare stakeholders**. Prof. Hornberger points to the value of networking among all healthcare stakeholders (including academics like himself): "*From an academic perspective, we're working much closer with patient-advocacy groups and charities. Together, I think this is really where we can hopefully push each other to bring more expertise to the table, and support each other.*"

Barriers and solutions to attaining a timely diagnosis of Alzheimer's disease
Download: https://bit.ly/39pqoAQ

← **Barriers include**		**Actions that help include** →
← Rapidly increasing prevalence ← Outpacing resourcing in high, medium and low-income countries ← Many remain undiagnosed	← Lack of consensus and clinical awareness of signs and symptoms ← Lack of pathways for differential diagnosis within dementias ← Few national plans with patchy implementation ← Lack of culture-specific diagnosis, e.g. people with low literacy ← Low public and clinical awareness of the benefits of timely diagnosis ← Stigma, and perception of Alzheimer's disease as `natural ageing'	→ Increasing awareness of the value of timely diagnosis for public and clinicians → Increasing adoption of technologies e.g. mobile, digital, Artificial Intelligence, blood tests, data integration → Identifying and addressing health inequalities in diverse cultures, and providing culture-specific diagnostic tools → Increasing networking and co-operation between carers/ patient groups → Increasing group engagement with regulators, policymakers and other stakeholders

Timely diagnosis of Alzheimer's disease

Source: PatientView, 2022

An important caveat

However, all of the above can only be made possible when appropriate investment and political will are both available. Thus far, civil society has been the only major actor pushing for institutional change to bring more resources to the task of tackling dementia/Alzheimer's disease.

Paola Barbarino notes: "*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 (the public and) a scientific community that is doing fantastic work. The challenge is to translate it towards 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.*"

Signs of hope for the future

Alzheimer's Disease International was instrumental in the World Health Organisation's 2017 decision to articulate a global action plan for dementia. The governments of many countries have since indicated a wish to adopt this plan—but, then, often fail to provide the resources needed to do so.
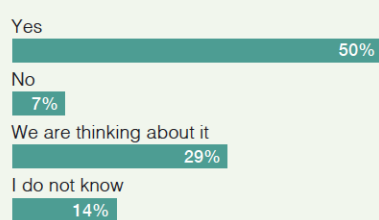
PatientView, press release, May 2022

Carer/patient groups involved with dementia/Alzheimer's know that they need to work hard to move the subject of dementia higher up the priority list of governments, particularly if the challenges facing *timely diagnosis* of Alzheimer's are to be resolved. As Prof. Hornberger stated: "*I think civil society do incredible engagement-and-policy work. But I think we really need to mobilise much more.*"

On a hopeful note, when the carer/patient groups attending the PatientView February 2022 Alzheimer's webinar were polled during the discussions, they indicated their willingness and confidence to work to change national agendas—with the aim of attaining more *timely diagnosis* of Alzheimer's disease.
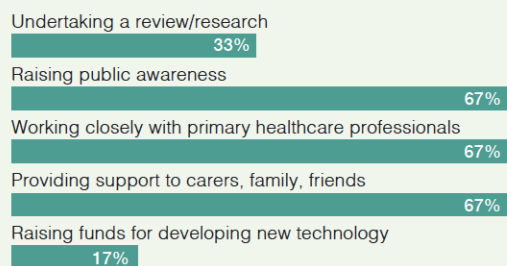
Poll of the attendees of the webinar I
Carer/patient organisations participating in the webinar were asked:

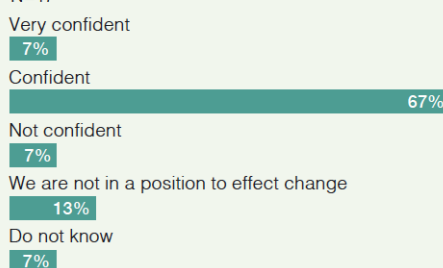**Is your patient/carer/advocacy group currently involved in discussion on timely diagnosis of Alzheimer's or dementia?**
N=17

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/de-mentia? (Participants could select more than one option.)
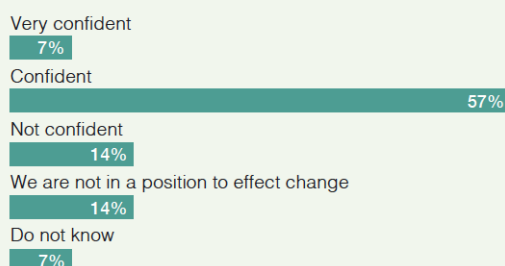N=17

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%

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%

Download poll 1: https://bit.ly/3vTLcrT; Download poll 2: https://bit.ly/3LvoM6I

When panellists to the February 2022 Alzheimer's webinar were asked about their hopes for timely diagnosis of Alzheimer's disease being achieved in the near future, John Schall stated: *"What I would most like to see in the next five years is for the reticence, the hesitation, and the feeling of resignation among families to go away in terms of trying to get an early diagnosis of Alzheimer's disease for their loved ones."*

Download details
of the report and accompanying resources

▶ *To watch the **webinar***
▶ *To get the **report***

- END OF PRESS RELEASE -

For further information on this report, please use contact details at the head of the press release.