



Young-onset dementia: changing perceptions in diagnosis

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Why is diagnosis important?

944,000

people are estimated to be living with dementia in the UK.

152m

cases worldwide estimated by 2050

We believe diagnosis should take place **earlier** and be more **accurate**.

It is the key to:

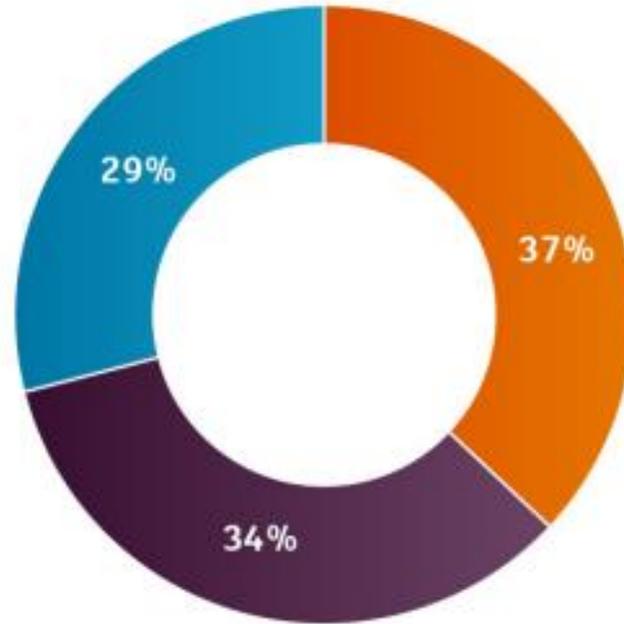


Perceptions around diagnosis:

1. Desire for pre-symptomatic diagnosis
2. Desire for symptomatic diagnosis
3. Willingness to undergo diagnostic tests

1. Public desire for pre-symptomatic diagnosis is higher than psychiatrists think

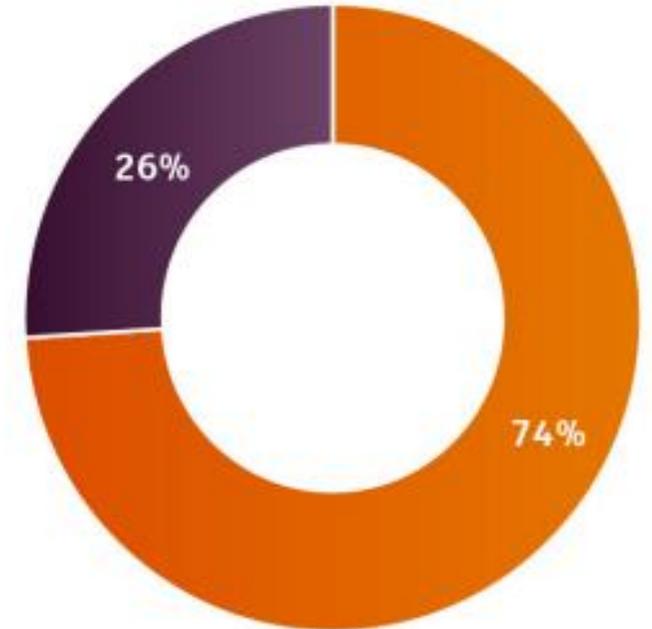
Psychiatrists underestimate the public's desire for receiving an early diagnosis of Alzheimer's disease.



● Agree ● Neutral ● Disagree

Psychiatrists: do you agree the majority of the public would want to know they had Alzheimer's disease prior to the onset of symptoms?

Source: Are we ready for new treatments? ARUK 2020



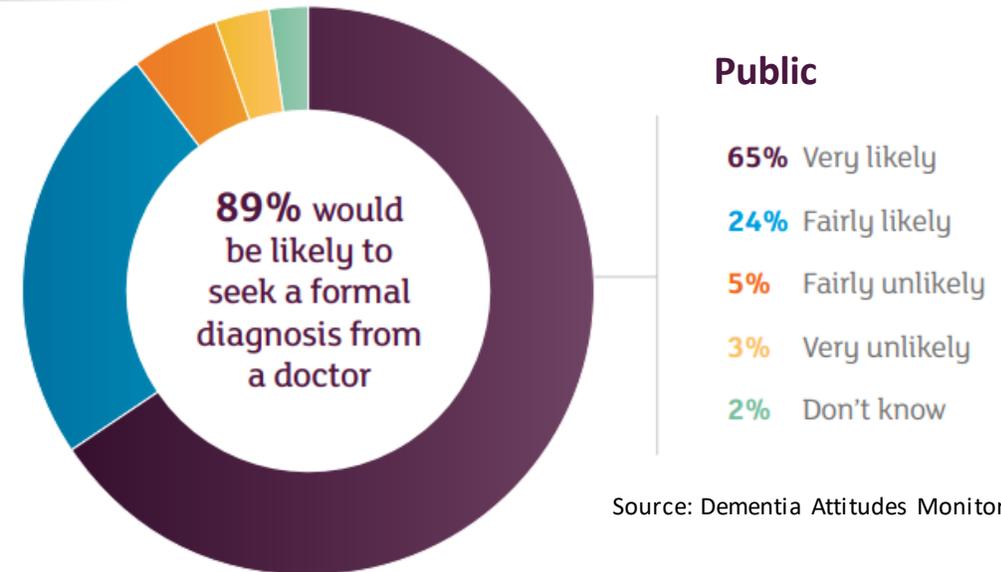
● Agree ● Disagree

Public: would you want to know if you had Alzheimer's disease before symptoms develop?

Source: Detecting and diagnosing Alzheimer's Disease ARUK 2019

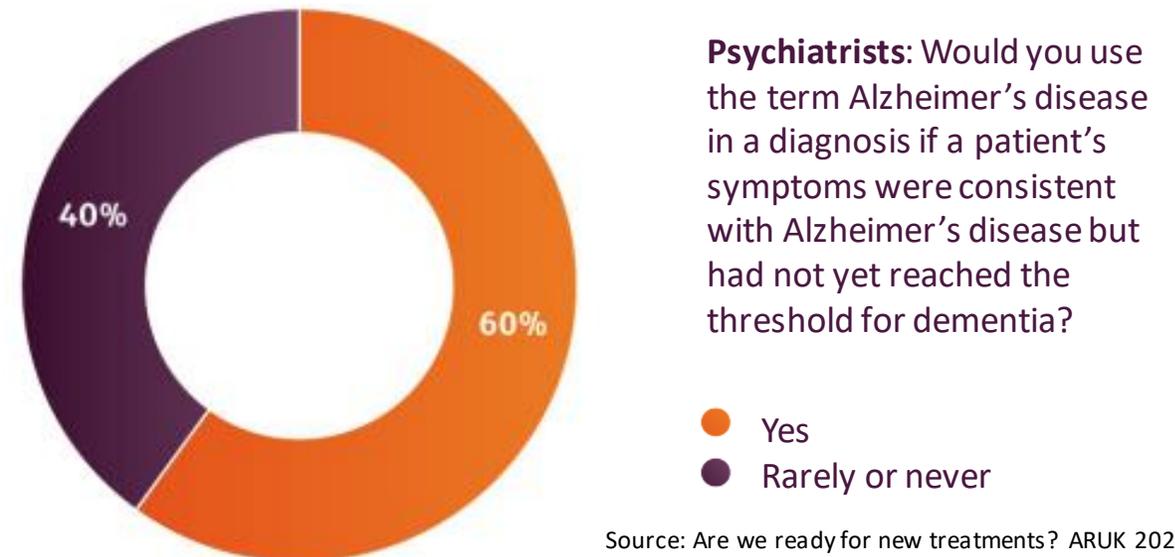
2. Public desire for formal diagnosis is high, but psychiatrists are uncertain about communicating one

Vast **majority of people** would be likely to seek a formal diagnosis if they were concerned about dementia.



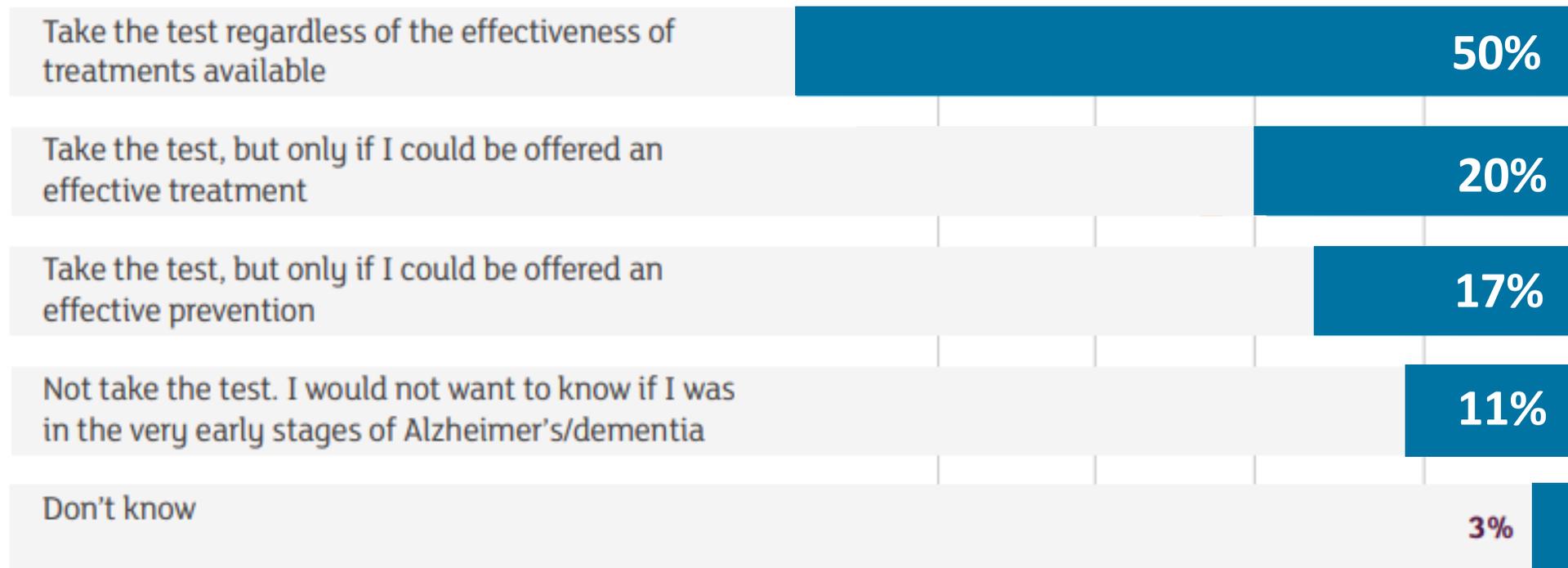
Source: Dementia Attitudes Monitor (wave 2) 2021

Psychiatrists are less certain about communicating a diagnosis of early Alzheimer's disease to patients.



Source: Are we ready for new treatments? ARUK 2020

3. Public desire for diagnosis and testing is high, even in the absence of a disease modifying treatment



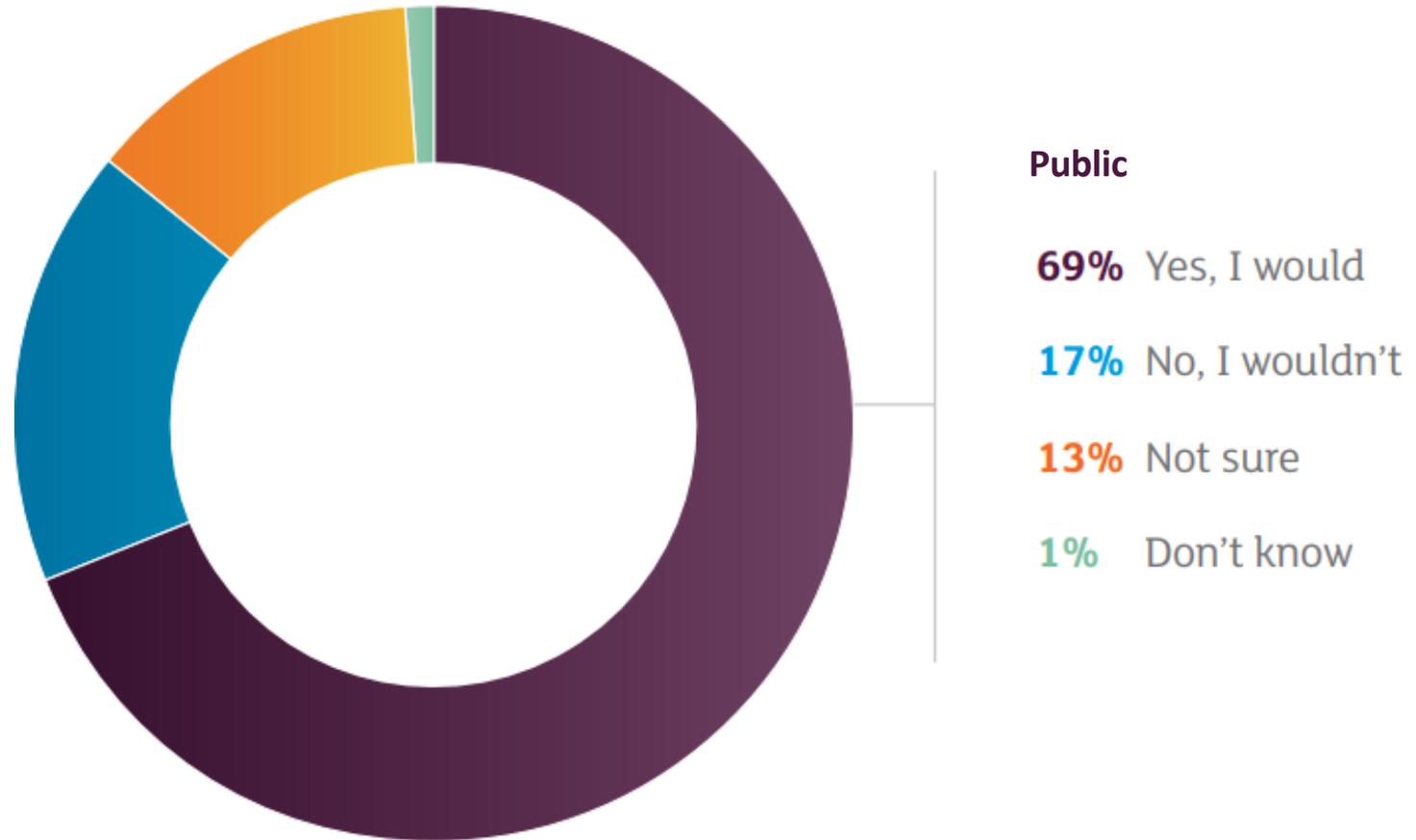
Perceptions around new dementia treatments:

1. Willingness to participate in research for new treatments
2. What people want from new treatments
3. Appetite for risk in a new treatment

1. Willingness to get involved in medical research is high, but it isn't routinely discussed in memory clinics

In 2021, **69%** of UK adults said they would consider getting involved in medical research, mainly driven by a belief that research is 'the only answer to dementia'.

In the same year, the Memory Assessment Services Spotlight revealed **only 24%** of patients were asked about medical research during their memory assessment service appointment.



2. What people want from new dementia treatments?

Based on a public survey with over 5800 responses:

- Key finding: the **most important outcomes for the public** are not those included in the Clinical Dementia Rating Scale (CDR):
 - memory, orientation, problem solving, community affairs, home and hobbies, personal care
- Views were **not dependent** on whether people had a **diagnosis of dementia**.
- The **direct lived experience** of people with memory problems is critical to finding sensitive **outcome measures**.

Most important outcomes for public

- **Reading & writing**
- **Driving**
- **Interactions with friends and family**
- **Supporting or caring for others**
- **Meaningful conversations**

3. Benefit/risk trade-offs people are willing to make with new dementia treatments

Project explored the risks that an individual would be willing to accept for the benefit of delaying progression of disease.

Key findings

- **More than half** of respondents were willing to **accept very high risks**.
- Living with memory problems or having **lived experienced** of dementia as a carer did **not change risk tolerance**.
- **More tolerance** to moderate side effects if **younger, male, higher' educational attainment or living alone**.
- Generally **greater tolerance for side effects** than found in previous studies than for **other chronic diseases**

Useful links

- ARUK and RCPsych 2021: Are we ready to deliver disease modifying treatments?
<https://www.alzheimersresearchuk.org/about-us/our-influence/policy-work/reports/are-we-ready-to-deliver-disease-modifying-treatments/>
- ARUK Dementia Attitudes Monitor 2021 https://www.dementiastatistics.org/wp-content/uploads/2021/09/ALZ_DAM_long-Report_21_LR_WEB_FINAL2.pdf
- National Audit of Dementia: Memory Assessment Services Spotlight 2021
https://www.hqip.org.uk/wp-content/uploads/2022/08/Ref-317-NAD-Memory-Assessment-Services-Spotlight-Audit-2021_FINAL.pdf



**THANK
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**Alzheimer's
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possible

Registered charity numbers: 1077080 & SC042474