



# Join Dementia Research: a government and charity partnership

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# The challenge

*“People with dementia and their carers are not routinely offered the opportunity to participate in high-quality research.”*



# Join Dementia Research

- Online and telephone system to connect people interested in dementia research to studies
- Funded by the UK Department of Health
- Delivered by National Institute for Health Research in partnership with three dementia charities



# Join Dementia Research

- Ethically approved research studies only
- Matches volunteers and studies using eligibility criteria
- Volunteers give consent to be approached by suitable studies



The screenshot shows the homepage of the 'Join dementia research' website. At the top, there is a navigation bar with a search field and a 'LOG IN' button. Below this is the 'Join dementia research' logo and the NHS logo with the text 'National Institute for Health Research'. A secondary navigation bar contains links for 'Home', 'About the service', 'How it works', 'Why sign up?', 'Any questions?', and 'For professionals'. The main content area features a large image of a woman looking at a laptop with the text 'WHO CAN HELP RESEARCHERS TO BEAT DEMENTIA?' and 'YOU'. To the right of this image is a large pink graphic with the text 'SIGN UP TODAY'. Below the image, there is a welcome message: 'Welcome to 'Join dementia research', a place to register your interest in participating in dementia studies.' This is followed by a paragraph explaining that anyone can register as a volunteer and that the service is currently being tested, primarily for the North London area. At the bottom, there are sections for 'What's new' and 'Your stories', and a 'Key things you should know about the service' section with bullet points: 'Sign up today', 'Answer as many of the questions as you can', and 'View the studies you match to'.

# Who can register?

- People with or without dementia or memory problems
- People who care for someone or have a family member with dementia
- A carer or next of kin can sign up on behalf of someone else providing they have their consent
- Anyone over 18 with an interest in research

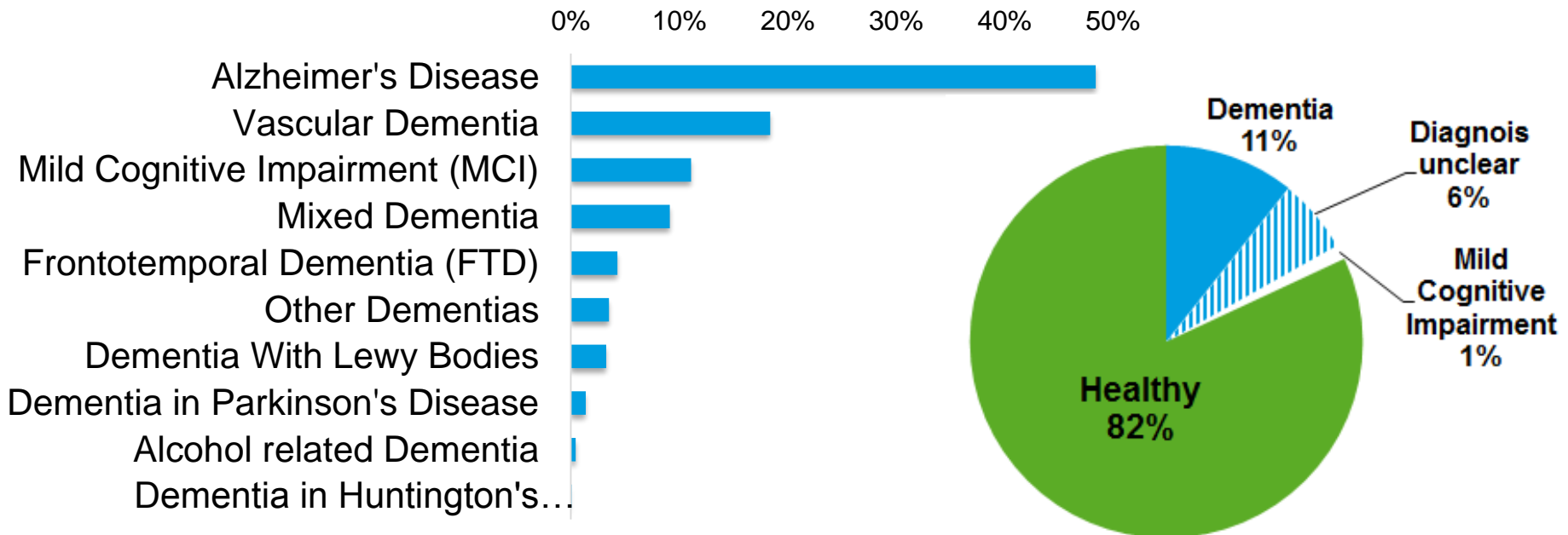
## How is Alzheimer's Society involved?

- Advisors on the design, governance and delivery groups
- Telephone helpdesk service to register those who are unable to complete the online registration themselves.
- Promotion of the service to researchers, our service users and general public
- Referral service for memory clinics and general practitioners



## Progress in 1<sup>st</sup> year

- 17,400 volunteers have registered
- 5000 people are taking part in 62 different studies

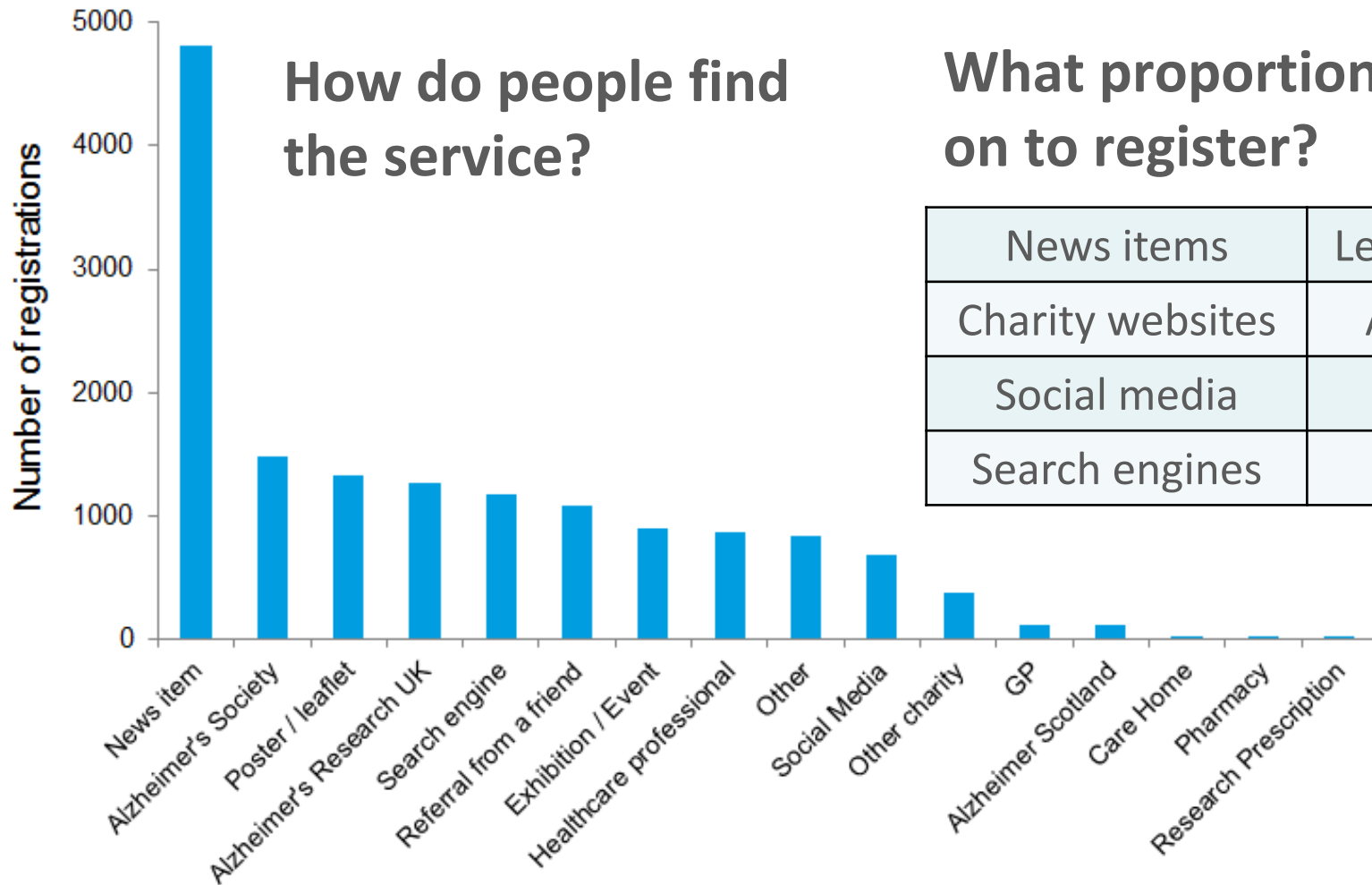


## Creating new opportunities

**86% of participants did not know how to get involved in dementia research before they joined**

**Before registering, 93% of participants had never been approached about taking part in dementia research**





### What proportion go on to register?

News items	Less than 10%
Charity websites	About 20%
Social media	8%
Search engines	6%

## Benefits for volunteers

- Empowered to learn about research taking place in their area
- More opportunities to take part in research studies
- Better understanding of dementia, access to experimental treatments and additional health visits
- Satisfaction of contributing to improved dementia care



# Benefits for the research community

- Finding eligible participants is easier and more efficient
- Research projects can be quicker and cheaper!
- Better designed studies due to feasibility function



# Benefits for Alzheimer's Society

- Better equipped to support people interested in dementia research
- More efficient recruitment for our own funded studies
- Engagement with a wider audience
- Expanded our corporate partnership offer

# Prime Minister's challenge 2020



*“...to have 25% of all people diagnosed with dementia registered on Join Dementia Research by 2020.”*

## Per year in England:

- 150,000 cases of dementia
- 100,000 cases with a diagnosis
- 25,000 people with dementia registering to the service



Find out more at:

[www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)

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