



# Government - charity partnership boosts participation in dementia research

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**Alzheimer's Society**



# The challenge

- Recruiting participants increases the time and expense of dementia research studies
- i.e. an 18 month clinical trial can take 18 months to fully recruit
- People living with dementia are not routinely offered the opportunity to take part in research



# Join dementia research

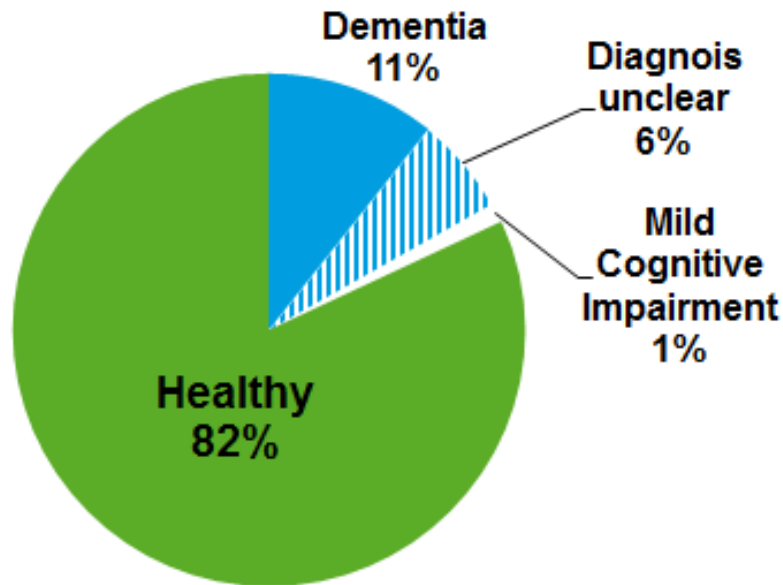


- Online and telephone system to connect people interested in dementia research to studies
- Funded by the UK Department of Health
- Delivered by National Institute for Health Research in partnership with three dementia charities



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

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

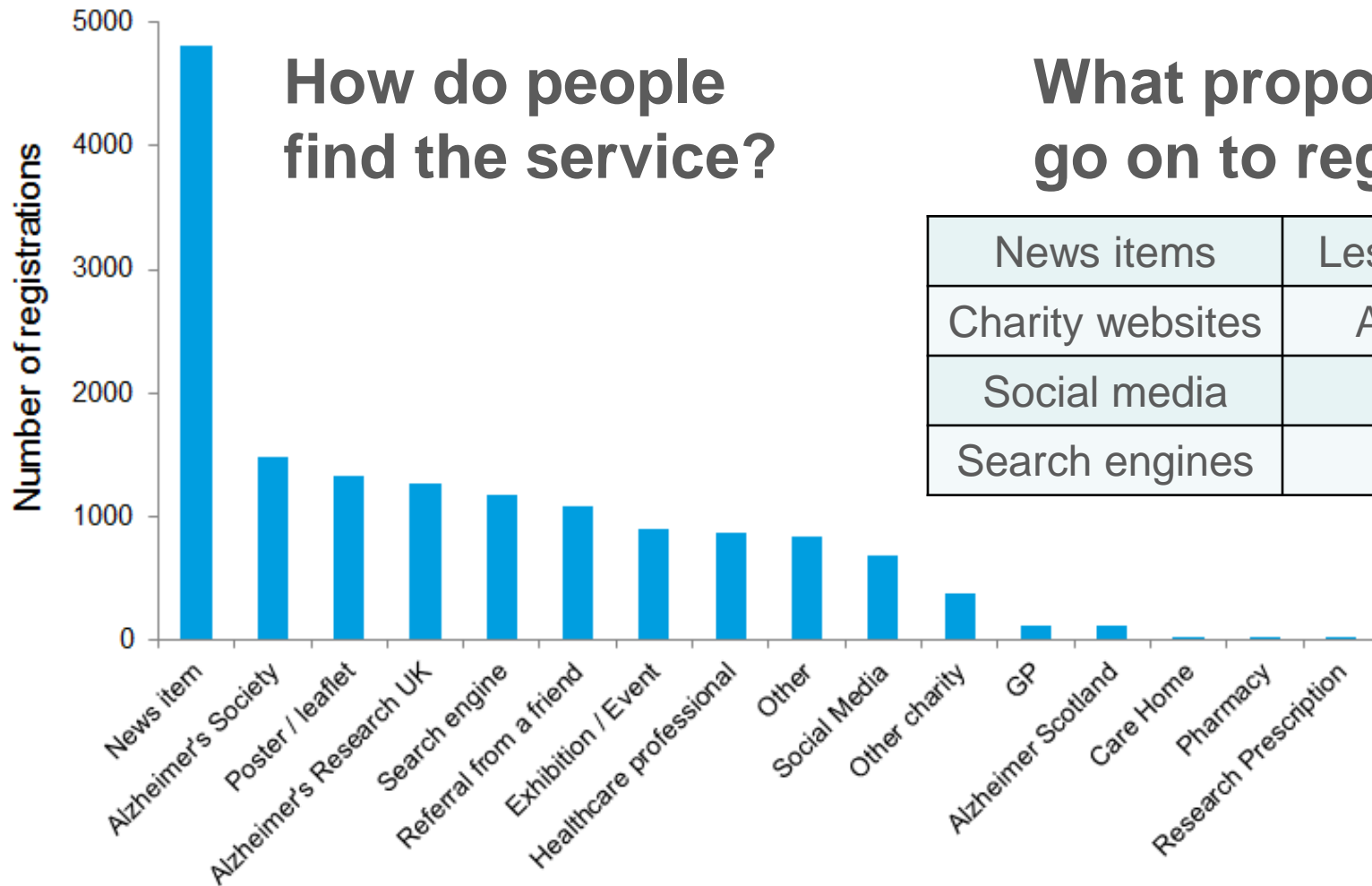


86% of participants did not know how to get involved in dementia research before they joined

# Prime Minister's challenge 2020



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



**What proportion go on to register?**

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

# Reaching people with dementia

- Alzheimer's Society are in touch with people with dementia and their carers and family members
- Support services – 87,000 people a year
- Helpline – 41,000 enquiries a year



# Call-back service – a pilot

- Professionals working with families affected by dementia can refer to our helpline
- We call their clients to help them register for Join Dementia Research
  - Memory service
  - GP surgery
  - Dementia Support Workers





# Call-back service – a pilot

**Clinician / support worker  
takes contact details**

**Helpline call – introduce service**

**Volunteer information sheet and  
checklist by email / mail**

**Helpline call – complete registration**

# Call-back service – a pilot

Clinician / support worker  
takes contact details

n = 44

Helpline call – introduce service

Failed or  
inappropriate  
n = 11

n = 33

Volunteer information sheet and  
checklist by email / mail

Failed or  
declined  
n = 9

n = 24

Helpline call – complete registration

Conversion rate = 55%

# Survey of the pilot sites:

- 90% of professionals in pilot were happy to refer their clients
- Main reasons for not referring:
  - Client not interested in research (memory clinic)
  - Inappropriate time to discuss it (support workers)
  - Client not confident to use the phone
- No-one listed lack of time to discuss research as the main reason

# Conclusions from our pilot work:

- A labour intensive process, but lots of **benefits**:
  - ✓ Easy for the referring professional
  - ✓ Less stressful and more reassuring for the person with dementia
  - ✓ High conversion rate
  - ✓ More complete registrations
  - ✓ Greater likelihood of matching to a research study



# Thank you for listening

## Hear more about Join Dementia Research:

- **OC051: Sat 23<sup>rd</sup> 14:00** – Increasing opportunities for people to take part in dementia research. How well is Join Dementia Research addressing the challenge?
- **P075:** An analysis of the first 60 studies using Join Dementia research - Poster session 2
- **P180:** How is recruiting from a research register different? Poster section 2