Government - charity partnership boosts participation in dementia research

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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

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Progress in 1\textsuperscript{st} 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.”
How do people find the service?

What proportion go on to register?

<table>
<thead>
<tr>
<th>Source</th>
<th>Proportion</th>
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<tbody>
<tr>
<td>News items</td>
<td>Less than 10%</td>
</tr>
<tr>
<td>Charity websites</td>
<td>About 20%</td>
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<tr>
<td>Social media</td>
<td>8%</td>
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<tr>
<td>Search engines</td>
<td>6%</td>
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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

Helpline call – introduce service

Volunteer information sheet and checklist by email / mail

Helpline call – complete registration

Failed or inappropriate: n = 11

Failed or declined: n = 9

Conversion rate = 55%

n = 44

n = 33

n = 24

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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 23rd 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

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