Join Dementia Research: a government and charity partnership

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Alzheimer’s Society

alzheimers.org.uk
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
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 1st year

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

Dementia in Huntington's...
Creating new opportunities

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

86% of participants did not know how to get involved in dementia research before they joined.
How do people find the service?  

<table>
<thead>
<tr>
<th>Method</th>
<th>Number of Registrations</th>
</tr>
</thead>
<tbody>
<tr>
<td>News item</td>
<td>5000</td>
</tr>
<tr>
<td>Alzheimer’s Society</td>
<td>3000</td>
</tr>
<tr>
<td>Poster / leaflet</td>
<td>1000</td>
</tr>
<tr>
<td>Alzheimer’s Research UK</td>
<td>1000</td>
</tr>
<tr>
<td>Search engine</td>
<td>1000</td>
</tr>
<tr>
<td>Referral from a friend</td>
<td>800</td>
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<tr>
<td>Exhibition / Event</td>
<td>800</td>
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<tr>
<td>Healthcare professional</td>
<td>700</td>
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<tr>
<td>Other</td>
<td>600</td>
</tr>
<tr>
<td>Social Media</td>
<td>500</td>
</tr>
<tr>
<td>Other charity</td>
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<tr>
<td>Alzheimer Scotland</td>
<td>400</td>
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<td>GP</td>
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<tr>
<td>Pharmacy</td>
<td>300</td>
</tr>
<tr>
<td>Research Prescription</td>
<td>300</td>
</tr>
</tbody>
</table>

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

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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

alzheimers.org.uk
Find out more at:  
www.joindementiaresearch.nihr.ac.uk

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