WHO CAN HELP RESEARCHERS TO BEAT DEMENTIA?

YOU

www.joindementiaresearch.nihr.ac.uk
Join Dementia Research - how can you be engaging with it?

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What is Join Dementia Research?

…a nationwide online and telephone service that will help you find, discover and take part in vital dementia research studies

www.joindementiaresearch.nihr.ac.uk
So what are the benefits of signing up?

**Find** studies matching your information

**Connect** with researchers and express an interest in their studies

**Discover** exciting new studies

**Help** to improve dementia care and treatment

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What kind of studies?

...from clinical trials of new treatments to surveys identifying what works in improving the quality of life for people with dementia.

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Who can help dementia research?

- Anyone with and without dementia over the age of 18 can register and people can register on behalf of someone else.

- Those registered do not have to take part in any studies. It is always their choice to take part or not.

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How does it work?

• Promoted to potential volunteers
  *Memory Clinics, Hospitals, GP Surgeries, Charities, Champions, Public*

• Anyone over 18 can join. People with dementia, carers, healthy controls.

• Join via charity helplines / website / paper application form

• Registration details to enabling matching
  *Name, address, telephone, date of birth, sex, diagnosis, dementia medication, health problems, disabilities, carer*
How does it work?

[Join Dementia Research Animation]
Volunteer experience

Update or add information

View studies you or volunteer matches

Show your interest

Sign-up for someone else

Read a lay summary

Review locations
Benefits for volunteers

• Opportunity to participate in research
  Drug Studies / Care Studies / Treatments / Diagnosis / Prevention
  Observational and Interventional

• Raising awareness of research

• Easier access to research across the country

• Improved patient experience when engaged in research and own healthcare
Benefits for researchers

• Direct access to volunteers and faster recruitment
• Improved screening rates
• Faster & more accurate feasibility assessments
• Improved study funding applications
• An engaged and interested group of volunteers
Safety and ethics

• It is safe and secure
• It only accepts ethically-approved studies
• It is approved by HRA
• It is funded by DH
The story so far - volunteers

18% join via helpdesk / mail

Healthy Volunteers
75% Women / 25% Men
Memory Problems
48% Women / 52% Men

41% of everyone registered with a diagnosis now in a study

18,034 total volunteers
The story so far - research

- 594 trained researchers
- 122 NHS, University & Commercial sites recruiting
- 28% of all volunteers participating in studies
- 21,095 screenings
- 65 Studies open to recruitment
- 18,034 total volunteers
- 72 Studies have recruited
- 5075 volunteers enrolled
What comes next?

• To meet the Prime Ministers 2020 Vision
What comes next?

- New simple service for healthcare professional to help volunteers register
- Volunteer mobile application
- Multimedia information on studies
- Dynamic data collection to improve screening
- Improved functionality and study matching
- Improved portal for researchers
- Dynamic consent management
How you can get involved

• Make sure your Trust is using Join Dementia Research for recruitment to dementia research studies

• Encourage promotion of Join Dementia Research to your hospitals’ patients directly

• Encouraging hospital staff to promote to their patients

• Contact your local Division 4 Research Delivery Manager