Increasing opportunities for people to take part in dementia research: How well is Join Dementia Research addressing the challenge?

Piers Kotting
National Institute for Health Research (UK)
Overview

What is the challenge?

What is Join Dementia Research?

Has it addressed the challenge?

What’s next?
WHAT IS THE CHALLENGE?
Growth of UK dementia research capacity

Recruitment to NIHR portfolio dementia studies

- Recruitment
- Studies open

Studies completing on time to target

- 2006/07: 30%
- 20014/15: 80%
But…

Current participation rate: 5%

2020 target participation rate: 10%

Public willingness to participate: 62%

Public knowledge about how to participate: 19%
“People with dementia and their carers are not routinely offered the opportunity to participate in high-quality research and there is no nationally consistent system to enable them to do so.”
How it works now

Researchers need volunteers

They find them in memory clinics

Post code lottery – motivated volunteers can’t join research studies

Effective – but can be slow, and depends on right people coming along
How we want it to work

Researchers need volunteers
They find them in memory clinics
They also use ‘Join dementia research’

Motivated volunteers have improved opportunities @ or beyond local hospital

Quickly find volunteers, according to own criteria + people who want to become involved
WHAT IS JOIN DEMENTIA RESEARCH?
Community of consented volunteers

Business processes & governance arrangements

National database of researchers and studies

Join dementia research
Welcome to 'Join dementia research', a place to register your interest in participating in dementia research.

Dementia affects 850,000 people in the UK.

The only way to beat the condition is through research.

Help us beat dementia
Anyone, with or without dementia, can register as a volunteer or sign-up for someone providing that you have their consent.
Sign up is the first step in becoming involved in supporting vital research studies across the nation.

Join dementia research - the numbers so far...

- 17,135 Volunteers
- 4,921 Volunteers Enrolled in Dementia Studies
- 115 NHS, University & Commercial Research organisations
- 566 Trained Researchers
- 62 Research studies
HAS JOIN DEMENTIA RESEARCH ADDRESSED THE CHALLENGE?
Has JDR increased awareness about dementia research and made it easier to take part?

Are people signing up from all areas of the country?

Is JDR facilitating recruitment of people into studies?
Are people signing up?

17,541 total volunteers

West of England
Yorkshire and Humberside
Kent, Surrey and Sussex
Scotland
South West Peninsula
North Thames
East Midlands
Eastern
Wessex
West Midlands
North West Coast
South London
Thames Valley and South...
North East and North...
Wales
Greater Manchester
North West London
Northern Ireland
Who is signing up?

**Age**
- 18-39: 47%
- 40-55: 28%
- 56-75: 15%
- 76+: 10%

**Gender**
- Men: 55%
- Women: 45%

**Volunteers with dementia**
- All volunteers: 27%
- Men: 73%
- Women: 73%
Who is signing up?

Diagnoses

- Alzheimer's Disease
- Vascular Dementia
- Mild Cognitive Impairment (MCI)
- Mixed Dementia
- Frontotemporal Dementia (FTD)
- Other Dementias
- Dementia With Lewy Bodies
- Dementia in Parkinson's Disease
- Alcohol related Dementia
- Dementia in Huntington's Disease

Volunteer Type

- With a dementia
- Awaiting / no diagnosis
- Without dementia

0% 10% 20% 30% 40% 50% 60%
Is this making a difference to volunteers?

Before I found out about JDR I already knew how to get involved in dementia research.

JDR has increased my awareness of what dementia research is going on.

JDR has made it easier for me to take part in dementia research.

4479 people surveyed – 705 responses (15.7%)
Is this making a difference to researchers?
Is this making a difference to researchers?

Percentage recruitment from JDR by region

National average 13%
WHAT’S NEXT FOR JOIN DEMENTIA RESEARCH?
“By 2020, 25% of people being diagnosed with dementia will be registering on Join Dementia Research.”
How are we going to hit the 2020 target?

- Volunteer native mobile app
- Multimedia information on studies
- Dynamic data collection to improve screening
- NHS registration application
- Interoperability with NHS Electronic Health Records
- Improved functionality and study matching
- Online cognitive screening
Thank you!

www.joindementiaresearch.nihr.ac.uk

piers.kotting@nihr.ac.uk
+44 (0)20 3206 4960
@P kotting @Beatdementia