

Opportunities for Faculty of Old Age Psychiatry, Royal College of Psychiatry to support Join Dementia Research (JDR)

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Background

Join Dementia Research is a UK-wide service that allows people to register their interest in participating in dementia research and to be matched to suitable studies. The initiative was developed and delivered by NIHR in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. Central to the JDR service is a database of volunteers, representatives and studies with a front-end website.

The service has been running for more than four years. Join Dementia Research is approved by the Health Research Authority and acts as a 'consent to contact' database. It works like a 'match-making service' between public volunteers and researchers. It does not commit individuals to take part in research. Researchers can use this service to get in touch with volunteers who may be suitable for their study but volunteers can choose which studies to take part in with no obligation, and they can change their mind at any time. Partner charity help desks can offer more personalised support for anyone registered or looking to sign up.

To date the service has successfully recruited large numbers of volunteers and placed many in studies, however, we need to work with health and care professionals to help raise awareness of the service as part of best care for people with dementia.

Why it's important

1. Patients want to hear about research opportunities



A recent survey of Join Dementia Research volunteers (most of whom have a diagnosis) showed that:

- 78% (62 out of 80 respondents) would want to have been told about Join Dementia Research as soon as possible after their diagnosis
- 58% (81 out of 140 respondents) thought the best person to tell them about Join

Dementia Research would be their healthcare professionals

2. Talking about research meets the requirements of NICE and NHSE guidance

The need to share research opportunities and the use of Join Dementia Research are recommendations in:

- NICE Guidelines Dementia: assessment, management and support for people living with dementia and their carers,
- NHS England's Dementia: Good Care Planning Guidance.

Join Dementia Research provides a simple mechanism to meet these requirements as it matches registrants to relevant studies in real time.

3. It's a government priority

Join Dementia Research is an important tool in assisting the delivery of the Prime Minister's Challenge on Dementia and the Dementia 2020 Vision (published in 2012 & 2015) for which key aspirations include:

- Every newly diagnosed person with dementia and their carer receiving information on what research opportunities are available and how they can access these through JDR.
- All relevant staff able to signpost interested individuals to research via JDR.
- 10 percent of all people diagnosed participating in research from a baseline of 4.5%.
- 25 percent of people diagnosed with dementia in 2020 registered on JDR (currently estimated to equate to 116,450 people with dementia or MCI registered in 2020).

Tools that can help Healthcare professionals

1. Short online awareness tool: taking just 10 minutes to complete, it is designed to help healthcare professionals understand why dementia research is important for their patients, and how talking about Join Dementia Research can help them deliver best care according to clinical guidance. <https://learn.joindementiaresearch.nihr.ac.uk/>
2. Free promotional materials from www.nihrresources.uk
3. Toolkit of ideas for how Join Dementia Research can be promoted to patients <https://nhs.joindementiaresearch.nihr.ac.uk/>
4. monthly data on CCG /STP progress towards recruiting 25% of people with dementia diagnosis on Join Dementia Research <https://nhs.joindementiaresearch.nihr.ac.uk/data-and-statistics/>