

## Opportunities for Faculty of Old Age 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 is JDR 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).

## JOIN DEMENTIA RESEARCH

MAKES IT EASY FOR ANYONE TO TAKE PART IN ETHICALLY APPROVED DEMENTIA RESEARCH



### 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](http://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/>

**Is there a role for the Faculty of Old Age Psychiatry to help?**

The National Institute for Health Research (NIHR) has been working with NHS England, Alzheimer Scotland, Alzheimer's Research UK, and Alzheimer's Society to deliver the objectives but successful delivery needs local ownership and drive, particularly from Old Age Psychiatrists.

In particular can we as a Faculty help to strengthen, promote and support use of JDR (and research generally)? It could help Trusts to meet the new CQC requirements relating to embedding research in clinical practice.

Potential actions include:

- Promote JDR in local clinics (including meeting the MSNAP standards 1.2.6 and 1.2.7)
- Letting our trainees know about JDR.
- Promoting JDR in your services.
- Help to disseminate the online 'LEARN' tool and encourage trusts and individuals to use it
- Linking with local DeNDRoN team