Join Dementia Research
Nicola McMillan (CRN JDR Manager) and Laurie Oliva (CRN National Head of Public Engagement)

Join Dementia Research is funded by the Department of Health and Social Care and delivered in partnership by:

An online and telephone service that helps patients and the public find and take part in vital dementia research studies.

Delivered in partnership by NIHR CRN, Alzheimer’s Society, Alzheimer’s Research UK and Alzheimer Scotland
How does the service work?

VOLUNTEER REGISTRATION - YOUR PATIENT SIGNS UP ONLINE, BY PHONE, OR BY POST

STUDIES ADDED - RESEARCHERS UPLOAD STUDY INFORMATION

MATCHING - THE SYSTEM MATCHES REGISTERED VOLUNTEERS TO SUITABLE STUDIES

CONTACT - RESEARCHERS GET IN TOUCH WITH VOLUNTEERS TO EXPLAIN ABOUT THE STUDY

VOLUNTEER DECISION - VOLUNTEERS DECIDE WHETHER OR NOT TO TAKE PART IN EACH STUDY, WITH NO OBLIGATION

Join Dementia Research in numbers

47,889 volunteers registered
44,409 participants have joined a study
472 studies have used the service
38 studies are currently open to recruitment
1,517 researchers have been trained to use the service
293 research sites have used the service

Data cut: 30/09/2020
Why embed JDR into patient pathways?

A 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

We also know that:

- Giving people the opportunity to participate in research gives them hope and a crucial sense of agency
- Even where people do not sign up they like to be given the opportunity!

Talking about research helps meet 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 recommendations as it matches registrants to relevant studies in real time.
Tools to help you

- 10 minute online dementia research awareness tool. 
  [https://learn.joindementiaresearch.nihr.ac.uk/](https://learn.joindementiaresearch.nihr.ac.uk/)

- Free promotional materials from 
  [www.nihrresources.uk](http://www.nihrresources.uk)

- Toolkit of ideas for promoting Join Dementia Research to patients 
  [https://nhs.joindementiaresearch.nihr.ac.uk/](https://nhs.joindementiaresearch.nihr.ac.uk/)

- Monthly data on registrations of people with dementia diagnosis on Join Dementia Research, by CCG /STP 
Ways to promote the service

- Share information about the service in consultation
- Follow up with emails with further information about the service and information on how to join
- Post out paper applications or promotional materials to people with a dementia diagnosis
- Share our charity helpdesk contact information so that potential volunteers can find out more about the service over the phone
- We are planning to add a call back service to JDR where professionals will be able to sign patients

Find us or get in touch

e-mail: jdr.professionals@nihr.ac.uk

www.joindementiaresearch.nihr.ac.uk

@beatdementia