

# Beating Dementia through Research

Everyone should have the chance to participate in dementia research.

Researchers are delivering ground breaking dementia studies - looking for ways to prevent, diagnose and treat dementia, and deliver better care. More people are desperately needed for research to progress.



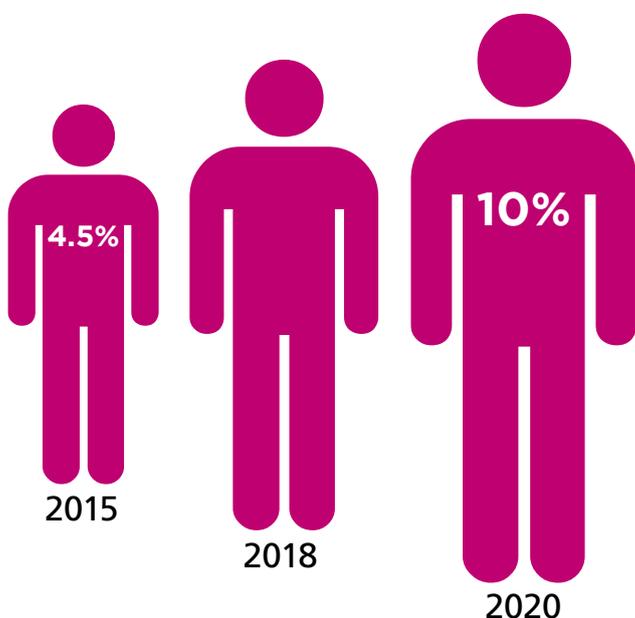
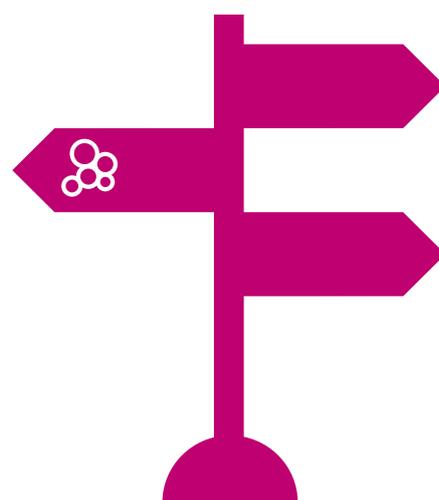
We urgently need more volunteers to come forward to help research, so we can accelerate the pace of discovery and benefit from the findings.

## Objectives by 2020



**1. Every newly diagnosed person** with dementia and their carer will receive information on what research opportunities are available and how they can access these through Join Dementia Research.

**2. All relevant staff will be able to signpost** interested individuals to research via Join Dementia Research.



**3. 25% of people with dementia** will be registered on Join Dementia Research.

**4. 10% of people with dementia** will be participating in a research study.

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## Objectives by 2020

### 1. Every newly diagnosed person with dementia and their carer will receive information on what research opportunities are available and how they can access these through Join Dementia Research.

- Within 12 months of receiving a dementia diagnosis, the patient is asked if they are interested in research and if so, are signposted to Join Dementia Research
- This could be delivered by the patient's healthcare team, as part of a post-diagnostic support service
- Where diagnosis takes place will depend on local care pathways, but this may include Primary Care, Memory Clinics, Secondary Care Neurology, Elderly Care or specialist Dementia Mental Health clinics
- Join Dementia Research printed and digital materials are available free of charge
- Information on local research studies is available from the NIHR Local Clinical Research Networks

### 2. All relevant staff will be able to signpost interested individuals to research via Join Dementia Research.

- 'All relevant staff' includes those who might interact with patients during the diagnostic and following care pathway. This can be agreed at a local level and may include doctors, nurses, psychologists, pharmacists, other healthcare professionals, receptionists and staff working in post-diagnostic support services
- Consideration should be given to how these staff are made aware of Join Dementia Research, how they are supporting this activity, what training they might need to understand how research works, how Join Dementia Research supports patients and the benefits of participation
- All of these staff could be in a variety of settings in Primary Care, Secondary Care or in the community

### 3. 25% of people with dementia will be registered on Join Dementia Research.

- This objective is to be achieved by December 2020
- The denominator is derived from NHS England published prevalence data
- The numerator is provided by Join Dementia Research based on the number of people registered with a formal diagnosis of dementia / Mild Cognitive Impairment (MCI)
- Support in understanding this objective in relation to a given area is available via the Office of the NIHR National Director for Dementia Research

### 4. 10% of people with dementia will be participating in a research study.

- Measurement of this objective will take place in 2020, up from the baseline of 4.5%.

#### Notes:

1. Localities should consider the research requirements in their area, and perform an assessment to understand what types of volunteers are needed to support study recruitment e.g. if studies need people without a diagnosis, local plans should also be flexible to include efforts to attract volunteers outside the care pathways.
2. The Office of the NIHR National Director for Dementia Research will start publishing data in 2018 to enable NHS organisations to monitor Join Dementia Research uptake, and delivery of Join Dementia Research objectives.
3. Monitoring of objectives will involve surveying patients and staff.
4. The Office of the NIHR National Director for Dementia Research has established the Enabling Research in Care (ERICA) Project to support delivery of the 2020 Dementia Challenge objectives for Join Dementia Research.