

## Dementia research service in the Eastern region registers 1000th volunteer

Dementia researchers in the East of England have hit a key milestone with over 1000 people in the region signed up to Join Dementia Research since launching a year ago. Join Dementia Research ([www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk)) is a nationwide online and telephone service that helps people to take part in dementia research studies.

Join Dementia Research acts like a 'matchmaking' service by linking members of the public who are willing to get involved in research with the dementia studies taking place, usually in their area. Once registered, the service identifies any studies a volunteer meets the criteria for and they are then sent an invitation to take part. The volunteer can then view the details of the study before deciding if they wish to go ahead and join it.

One of the studies recruiting for volunteers in the East of England is called IDEAL, which is identifying what changes can take place in the home and in the community to help people with dementia to live well. The study is looking for people with any form of dementia and their carers to take part in interviews in their own homes.

The 1000-plus volunteers who have already registered are a mix of those people who have been diagnosed with dementia, carers of people with dementia and healthy members of the public who want to help push dementia research forward. Vital studies in early diagnosis, prevention and new treatments are making good progress but more volunteers are needed to sign up.

Dr Ben Underwood is a NIHR's Clinical Lead for dementia research in the Eastern region and Consultant Psychiatrist at Cambridgeshire and Peterborough NHS Foundation Trust. He commented on the success so far, saying "The Eastern region and Cambridge in particular is an extremely active centre for dementia research. We currently have more than a dozen dementia studies running and are actively using Join Dementia Research to recruit to them, to a point where we have already exceeded this year's target for recruitment via the service. We are always grateful to the patients, caregivers and other members of the public who take part in these studies. Join Dementia Research provides a quick and easy way of accessing all the latest studies in dementia and means that people are automatically contacted whenever any new studies come up"

As Join Dementia Research Champion for the Eastern Region, volunteer Chris Carling is an active promoter of the service. She said, "Both my parents had dementia and we were effectively told nothing could be done for them. My aim in promoting Join Dementia Research is to work towards a time when something can be done – and this will be through research and more people taking part in research."

Dr Laura Phipps of Alzheimer's Research UK, the UK's leading dementia research charity, said "Join Dementia Research gives everyone a great opportunity to play a role in pioneering research to defeat dementia. This milestone highlights just how supportive people in the Eastern region have been and how willing they are to give their time to volunteer for studies. We hope that people across the region will continue to sign up to volunteer and inspire their

friends and family to do it too. Dementia is a heartbreaking condition but research can make progress for everyone affected.”

Dr Louise Walker, Research Officer at Alzheimer’s Society, said “It is great to see that so many local people are signing up to Join Dementia Research. Their generosity will help us to make real progress towards finding new treatments and understanding more about the causes of dementia. The more people who get involved in research, the stronger these studies are. We encourage anyone who may be interested in taking part to sign up, including people affected by dementia and their families. This service empowers people to be part of the crucial search for better care today and a cure for the future.”

If you would like to find out more or get involved to help researchers try and beat dementia visit [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk) or call either of the below charity helpline numbers:

Alzheimer's Research UK: 0300 1115111

Alzheimer's Society: 0300 2221122

### **Notes for editors**

For more information and interview opportunities please contact:

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### **About Join Dementia Research**

Join Dementia Research is funded by the Department of Health and delivered in partnership with the National Institute for Health Research, Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society.

1. Volunteers can register online by going to [www.joindementiaresearch.nihr.ac.uk](http://www.joindementiaresearch.nihr.ac.uk), or by phone or by post. Signing up is simple and involves giving some basic details. It is possible to sign up someone else if they would find signing up themselves difficult.
2. Current figures after the first year of operation are: 16,627 volunteers signed up across the country (more than 1000 in the Eastern Region); 4758 of these already enrolled in trials; 115 NHS, University and commercial research organisations involved; 62 research studies currently open on the JDR register.
3. People who sign up can withdraw from studies at any time without giving a reason. Withdrawing would in no way affect their care.
4. JDR is being promoted through NHS hospitals, GP surgeries, pharmacies and through charities such as the Alzheimer’s Society and Alzheimer’s Research UK.

### **About the NIHR Clinical Research Network**

1. The NIHR Clinical Research Network is part of the National Institute for Health Research. We provide researchers with the practical support they need to make clinical studies happen in

the NHS, so that more research takes place across England, and more patients can take part. This practical support includes: reducing the “red-tape” around setting up a study; enhancing NHS resources, by funding the people and facilities needed to carry out research “on the ground”; helping researchers to identify suitable NHS sites, and recruit patients to take part in research studies; advising researchers on how to make their study “work” in the NHS environment.

2. The NIHR Clinical Research Network pledged research delivery support to 1869 new clinical studies and recruited more than 618,000 patients to studies in 2014/15. More info is available at: [www.crn.nihr.ac.uk/annualstats](http://www.crn.nihr.ac.uk/annualstats)
3. NHS Trusts are ‘clustered’ into categories. ‘Cluster’ is the term used for a group of NHS organisations with similar characteristics, which allows comparisons to be made between Trusts in similar circumstances.