

NEWS RELEASE

Clinical Research Network
South West Peninsula

1,000 SW people signed up to *Join Dementia Research*

The South West is celebrating a key milestone with 1,000 volunteers signed up to a service which is boosting recruitment to dementia research studies.

Promoted locally by the NIHR Clinical Research Network, awareness about the *Join Dementia Research* service has been raised since the February launch at key research-related events and through NHS hospitals, GP practices, community pharmacies and dementia care homes, support forums, Alzheimer's Research UK and Alzheimer's Society.

Join Dementia Research is a free service which enables anyone with or without dementia aged over 18 to register by telephone or online their interest in dementia research. This register is proving to be a valuable resource for clinical research teams to quickly and effectively identify, match and recruit research participants.

Dr Ray Sheridan, Clinical Research Lead for the NIHR Clinical Research Network South West Peninsula, said: "There are currently 15 dementia research studies being conducted in the South West. We are always grateful to the patients, care givers and healthy members of the public who volunteer to take part in these studies so that we can improve the quality of life of people diagnosed with this condition and their families.

"Dementia is increasingly touching more of us and research gives hope. The prevalence of dementia in Devon, Cornwall and Somerset is 0.74% of the population compared with 0.57% nationally."

Senior Research Practitioner Nicola Walker at the Royal Devon & Exeter hospital cannot speak highly enough about the *Join Dementia Research* service saying: "With *Join Dementia Research* I was able to recruit the first patient to a study within 11 days of approval to open that study. It was a straight forward process because the *Join Dementia Research* service provides a register of volunteers who don't mind being approached to take part in studies. Matching the volunteers with studies made the 30-day first recruit target very manageable."

Nicola appreciated this resource because this is the first time she is the Principal Investigator for a study. She added: "On the day approval came through for us to locally

open the study I emailed four people registered with JDR and received a response from two of them within 24 hours who both agreed to participate. It is great to be able to offer people the opportunity to take part in a range of dementia studies requiring a range of commitment.”

She added: “This particular study is looking at detecting susceptibility genes for late-onset Alzheimer’s disease and involves one home visit by two researchers to carry out cognitive testing, a semi-structured interview and taking a blood sample.”

The Royal Devon & Exeter NHS Foundation Trust and Devon Partnership NHS Trust work together as the Devon Dementia Collaboration to set up and deliver dementia research studies.

Between April and November 2015 the total number of patients recruited to dementia studies in the South West (Devon, Somerset, Cornwall and the Isles of Scilly) was 104 and 46 of these were enrolled by the Devon Dementia Collaboration.

Clinical Studies Officer Jon Richards of Devon Partnership NHS Trust was the first in the South West to succeed in using the *Join Dementia Research* service to match and recruit a patient to a study.

Devon Partnership Trust Research & Delivery Manager Tobit Emmens said: “Recruiting participants for the dementia research studies we are running is a big challenge. At the same time, many people are looking for studies to contribute to and take part in, but don't know where to find out about them. With *Join Dementia Research*, everybody now has that chance to see what dementia research is taking place and enables them to connect to researchers and to participate in studies.”

Join Dementia Research registration couldn't be easier - By signing up to *Join Dementia Research* online (www.joindementiaresearch.nihr.ac.uk) or by telephone (Alzheimer’s Research UK 0300 111 5 111 or Alzheimer’s Society 0300 222 1122), volunteers agree to be contacted to see if they would like to take part in new studies being conducted in their local area.

This service is funded by the Department of Health and delivered by the NHS National Institute of Health Research in partnership with Alzheimer's Research UK, Alzheimer's Society and Alzheimer Scotland.

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Note to editors:

Media enquiries should be made to the NIHR Clinical Research Network South West Peninsula Communications Lead Wendy Shaw on 01752 431944 or wendyshaw1@nhs.net

A photograph is available for media of the Devon Dementia Collaboration receiving a *Join Dementia Research* recruitment certificate of merit from NIHR Clinical Research Network: South West Peninsula Chief Operating Officer Helen Quinn - Senior Research Practitioner Nicola Walker, Dr Ray Sheridan, Dr Ruth Newman, Dr Jo Butchart and Clinical Studies Officer Jon Richards.

About the NIHR

The Clinical Research Network is part of the National Institute for Health Research, which is the research arm of the NHS. We are a co-ordinated national network that enables and embeds high quality research as core business across health and social care to make people and the NHS better. We do this by:

- Ensuring that as many people as possible across England have the opportunity to participate in research;
 - Providing researchers with the practical support they need to make clinical research studies happen in the NHS;
 - Ensuring the efficient and effective delivery of high quality clinical research across the health community;
 - Attracting national and international clinical research investment; and
 - Providing a coordinated response to national research priorities
- www.crn.nihr.ac.uk

The NIHR Clinical Research Network: South West Peninsula is hosted by Royal Devon and Exeter NHS Foundation Trust. The host is responsible for ensuring the effective delivery of research in the Trusts, primary care organisations and other qualified NHS providers throughout the South West Peninsula area.