

Hundreds in South West back dementia research service

The South West is playing its part in the recruitment of volunteers to dementia research studies.

One year on from the launch of a groundbreaking service called *Join Dementia Research* almost 16,000 people nationally have signed up to this initiative which encourages people to register their interest in taking part in clinical research into this condition.

In the South West 1,110 volunteers have registered with *Join Dementia Research* service which provides a valuable resource for researchers in their search for potential dementia research studies.

To date 268 of the 1,110 registered from this region area of Somerset, Devon, Cornwall and the Isles of Scilly have been matched as potentially participants meeting the criteria for who may be eligible to take part in dementia research studies and 39 people have been recruited across 10 different studies.

Only one in three dementia research studies recruit enough volunteers within a year* – a challenge which can significantly slow down the progress towards better care, new treatments and ultimately a cure.

Hilary Doxford of Yeovil, Somerset, is a World Dementia Council member and is living with dementia. She is currently taking part in a research study looking at brain inflammation as dementia develops.

Speaking of her own experience as a research participant, Hilary said: “I have enjoyed taking part in the study and love being involved in research. I am well looked after, I have interesting discussions, gain an insight into the latest theories; I am aware of the latest results and it keeps my brain active.” She also believes research participation has given her a better understanding of the disease progression that she might otherwise have had.

Hilary is promoting *Join Dementia Research* when the World Dementia Council, which was set up from the G8 dementia summit in 2013, comes together for its Annual Meeting this month. (25 February 2016)

Dr Ray Sheridan, the NIHR Clinical Research Network for the South West Peninsula Clinical Research Specialty Lead for Dementias and Neurodegeneration, said the positive local support for the *Join Dementia Research* initiative has been heartening.

Dr Sheridan, a consultant physician in elderly care at the Royal Devon & Exeter hospital, said: “*Join Dementia Research* is a useful way of researchers finding ‘research friendly’ citizens diagnosed with this condition, care-givers or healthy members of the public as potential participants in a range of studies from questionnaires about the impact of the disease on quality of life to evaluating new clinical treatments and therapies.”

***Join Dementia Research* provides a national telephone service with charity helplines (Alzheimer’s Research UK 0300 111 5111 or Alzheimer’s Society 0300 222 1122) and an online (www.joindementiaresearch.nihr.ac.uk) service for people to register their interest in participation in research into this disease. It is funded by the Department of Health and delivered in partnership with the National Institute for Health Research, Alzheimer’s Research UK and the Alzheimer’s Society.**

It was launched as part of the Prime Minister’s Challenge of Dementia to increase the numbers of people with dementia participating in research. Dementia affects 850,000 people in the UK - a figure expected to rise to over one million people by 2021.

Life Sciences Minister George Freeman MP said: “I am delighted that so many people have signed up to *Join Dementia Research* in its first year and are now taking part in potentially life-changing studies. Positive action like this is exactly why we invest £1 billion each year through the National Institute for Health Research.

“But I hope this is only the beginning and would encourage more people, especially those with dementia, to join this vital service so they too can help in our fight against this condition.”

Hilary Evans, Chief Executive of Alzheimer's Research UK, said: Join Dementia Research is already showing its potential in making the UK one of the best places in the world to conduct cutting-edge dementia research and providing a variety of opportunities for people with the condition to engage with the latest developments. It's really important to spread the word about the service to provide everyone with dementia and their loved ones the opportunity to get involved."

Dr Doug Brown, Director of Research and Development at Alzheimer's Society, said: "Research is essential for us to make progress towards new dementia treatments and better care, but it can also empower people with dementia and their families to learn more about the condition and benefit from extra support."

Ends

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Notes to editors:

Media wishing to interview Hilary Doxford or Dr Ray Sheridan in relation to this press release should contact Wendy Shaw, Communications Lead for the NIHR Clinical Research CRN: SWP on 01752 431944 or email: wendyshaw1@nhs.net

For all other media enquiries about Join Dementia Research contact Andrea Fisher of NIHR Central Communications on 020 3206 4962 or email: andrea.fisher@nih.ac.uk

*A review of 24 multi-site Alzheimer's disease clinical trials found that only a third were able to recruit sufficient volunteers within a year – paper reference: <http://www.ncbi.nlm.nih.gov/pubmed/21172069>

Facts about dementia

- Dementia is used to describe a group of symptoms including memory loss, confusion, mood changes and difficulty with day-to-day tasks.
- Every 3.2 minutes someone in the UK develops dementia, and the number of people affected is predicted to double in the next 30 years.
- Dementia is caused by brain diseases, with Alzheimer's disease accounting for around two thirds of cases.
- One person will develop dementia every three minutes.
- Dementia costs the UK over £26 billion a year.
- There is no cure for Alzheimer's disease. Delaying the onset of dementia by five years would cut by a third the number of people affected by dementia.

About the service

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.

By signing up to the service, people give permission for researchers to contact them with details of studies in their area that match their profile. People can then decide if they would like to participate in those studies on a case-by-case basis. By registering, people do not have to take part in any studies and can opt-out at any time.

About the NIHR

The [National Institute for Health Research \(NIHR\)](#) is funded by the Department of Health to improve the health and wealth of the nation through research.

Since its establishment in April 2006, the NIHR has transformed research in the NHS. It has:

- increased the volume of applied health research for the benefit of patients and the public
- driven faster translation of basic science discoveries into tangible benefits for patients and the economy
- developed and supported the people who conduct and contribute to applied health research.

The NIHR plays a key role in the Government's strategy for economic growth, attracting investment by the life-sciences industries through its world-class infrastructure for health research.

Together, the NIHR people, programmes, centres of excellence and systems represent the most integrated health research system in the world.

About Alzheimer's Research UK

Source: <http://www.alzheimersresearchuk.org/>

Alzheimer's Research UK is the UK's leading dementia research charity specialising in finding preventions, causes, treatments and a cure for dementia. For more information about dementia research, contact the Dementia Research Infoline on 0300 111 5 111.

About Alzheimer's Society

Source: <http://www.alzheimers.org.uk/>

Alzheimer's Society supports people to live well with dementia today and funds research to find a cure for tomorrow. We rely on voluntary donations to continue our vital work. You can donate now by calling 0845 306 0898 or visiting alzheimers.org.uk

About Alzheimer Scotland

Source: <http://www.alzscot.org/>

Alzheimer Scotland helps people with dementia, their carers and families. Our members include carers, relatives, people with dementia, professionals, groups and organisations.