



NEWS RELEASE

**EMBARGO – Wednesday 20 May 2015 (00:01)
International Clinical Trials Day**

Public rally to volunteer for dementia research Over 6,000 sign up to Join Dementia Research

On International Clinical Trials Day (20 May), dementia researchers are celebrating a surge of public support with over 6,000 people signing up to Join Dementia Research to register their interest in volunteering for dementia research studies. The online and telephone service, which launched nationally in February, is already recruiting volunteers into research studies but those responsible for its development are urging more people to consider signing up.

Join Dementia Research (www.joindementiaresearch.nihr.ac.uk) is funded by the Department of Health and delivered by the National Institute of Health Research in partnership with Alzheimer's Research UK, Alzheimer's Society and Alzheimer Scotland. The initiative, the first of its kind in the UK, aims to provide the opportunity for those with dementia and their friends and family to get involved in pioneering research, as well as streamlining the recruitment process for researchers. By signing up, volunteers agree to be contacted to take part in new studies getting underway in their area, from which point they can decide if they wish to take part.

The scheme piloted in July 2014 and was launched nationally in February, with a surge of registrations in the last three months. There are now 39 different studies looking for volunteers through Join Dementia Research, and over 1,000 members of the public have already been enrolled into research.

Despite the initial success of the system, the people behind Join Dementia Research are calling for greater awareness of the initiative and encouraging more people with early memory problems to consider signing up.

Prof Martin Rossor, the NIHR National Director for Dementia Research, said:

"The fantastic response we've seen to Join Dementia Research so far is indicative of the importance of dementia and research to the wider public. With 850,000 people in the UK living with dementia, there is a collective agreement that more needs to be done, that research plays an important part in that progress and that the public are willing to donate their time to come together to make it happen.

"We need to maintain momentum to reach our aspiration for 100,000 people to sign up to Join Dementia Research. We still have a long way to go to spread the word about Join Dementia Research to people with dementia and their families living in towns and cities in every corner of the UK and make sure everyone knows that the opportunity is available to them."

Join Dementia Research allows anyone with and without memory problems to sign-up using basic demographic and health information and be matched to studies in their area. Research teams whose

studies are recruiting using Join Dementia Research can then approach them about their particular study and the volunteer can decide whether to take part on a case-by-case basis.

It's also possible to register on behalf of someone who may not be able to register themselves, acting as a representative. This allows people to sign up those who may need assistance using the system or may have dementia themselves and benefit from a helping hand.

One of the studies that has recruited the most people through Join Dementia Research is a ten-year study for healthy people over 50 called PROTECT, being run through King's College London. Volunteers are asked to complete online memory and thinking tests and provide an annual DNA sample to allow researchers to study brain ageing and risk factors for dementia. However, many of the studies on Join Dementia Research are looking for people in the early stages of dementia or those with mild cognitive impairment who are experiencing memory and thinking problems not yet severe enough to be diagnosed as dementia.

Dr Elizabeth Coulthard, a dementia researcher at the University of Bristol, is using Join Dementia Research to recruit volunteers with dementia for a brain imaging study. She said: "People with dementia who are willing to volunteer for studies are the life-blood of our research and are absolutely crucial if we are to keep making progress. We're looking for people with Alzheimer's disease and frontotemporal dementia as well as people with early memory problems and healthy volunteers for our study. We're asking volunteers to take a 30min MRI brain scan and do a memory test to help us develop better brain scanning techniques to detect the disease earlier. The more we can spread the word about Join Dementia Research the more everyone – researchers and people with dementia – will be able to benefit."

Hilary Doxford, who has dementia and was one of the first people to sign up to Join Dementia Research said:

"Without a cure we are reliant on research to find that cure or ways to help us live better with dementia for longer. Research cannot happen without people with dementia but it has been hard for researchers to find us and for us to find out about research opportunities and what it may involve. Join Dementia Research provides information and volunteering opportunities for research, which has given me something very positive to focus on. The involvement of people with dementia today will hopefully help not just us but so many in the future. I really would encourage anyone who has, or knows someone with, dementia to have a discussion about research and consider signing up to Join Dementia Research. It could be a positive step in your life too."

People are being asked to sign up online at www.joindementiaresearch.nihr.ac.uk or contact one of the charity helplines: Alzheimer Scotland (0808 808 3000), Alzheimer's Research UK (0300 111 5 111) or Alzheimer's Society (0300 222 1122).

Ends

For film and interview opportunities please contact Laura Phipps, Press Office (Alzheimer's Research UK): 0300 111 5 666 mobile: 07500803936.

Notes to Editors

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 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](http://www.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.