

Embargo until 00.01 on 24th February 2015

Pre-record and live broadcast opportunities available

Ground-breaking new national service empowers public to take part in vital dementia research

A nationwide online and telephone service that helps people to take part in dementia research studies launches today (24 Feb 2015). *Join Dementia Research* promises to accelerate the pace of dementia research by allowing people with and without dementia to register their interest in studies, helping researchers find the right participants at the right time. This new initiative has been developed as part of the Prime Minister's Challenge on Dementia and the launch follows Saturday's announcement of £300m for dementia research with a direct call for the public to get involved.

Join Dementia Research is a collaboration between the National Institute for Health Research (NIHR), Alzheimer's Research UK, Alzheimer's Society, Alzheimer Scotland and UCL Partners, and has been funded by the Department of Health and NHS England through the SBRI Healthcare Programme.

Dementia affects over 850,000 people in the UK, with 25 million of the UK population having a close friend or family member affected. A new national poll* has shown that almost two thirds of the general public (62%) would be willing to take part in dementia research, but more than four out of five people (81%) wouldn't know how to volunteer. *Join Dementia Research* is designed to overcome these barriers and give everyone the opportunity to play a role in changing the outlook for people with dementia now and in the future.

The lack of access to willing volunteers is holding back critical research into the condition with government figures showing that less than 5% of people with dementia take part in research studies. The first of its kind in the UK, this innovative new service will boost research participation by connecting people interested in research to suitable dementia studies across England, Scotland and Wales. After piloting the service in a small region for six months, more than 1,800 people have signed up and already over 200 of them have participated in studies through *Join Dementia Research*.

The joindementiaresearch.nihr.ac.uk website offers a secure and easy way for someone to register their interest, discover studies that interest them, and ultimately connect with researchers to take part in their studies.

Anyone aged 18 years or over can sign up themselves, or on behalf of someone else, either by registering online or by contacting the helplines of Alzheimer's Research UK (0300 111 5 111) and Alzheimer's Society (0300 222 1122). 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.

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

"The government and charities have increased funding for dementia research over the last

few years, meaning more studies are being done than ever before, but it's often difficult to find willing volunteers at the right time.

"*Join Dementia Research* offers a way of 'match-making' – linking volunteers to researchers. The system also helps us plan future studies. It's important that everyone should be able to find out about research that is happening near to where they live and get the opportunity to be part of that research. People can register with *Join Dementia Research* without being obliged to take part in a particular study, but we hope that the service will expand the pool of willing participants. Growing the number of willing research volunteers will help push forward research to make advances in treatment, prevention and care."

Secretary of State for Health, Jeremy Hunt, said:

"New research is desperately needed to help the growing numbers of people who live with dementia, which is why we're doubling the size of the funding pot. This is an important initiative, and I encourage anyone who is interested to visit the website or call the charity helplines to find out more about how they can help us tackle dementia."

Prof Dame Sally Davies, Chief Medical Officer for England, said:

"This superb initiative was developed to help ensure we can meet the ambitious targets for recruitment to high-quality research studies, set by the Prime Minister in his challenge on dementia. *Join Dementia Research* is a potential pathfinder for other fields, showing how to boost patient and public participation in research."

Sue Boex, one of the carers who helped design *Join Dementia Research*, said:

"This is a very exciting initiative, and one we really need people to get behind. Everyone can sign up, whether you have dementia or not, and there are lots of different types of studies to take part in. But because studies have very specific criteria, we need lots of people signing up in order to find the right people for the right study at the right time. I hope that 100,000 people will join the service in the first year. It's an ambitious target, but dementia is a massive problem and we're ambitious to help make a difference through research."

Speaking about this new service, Hilary Evans, Director of External Affairs at Alzheimer's Research UK, said:

"As a charity focused on dementia research, we're acutely aware of the tremendous impact volunteers make on research progress in dementia. We know there is a strong appetite from the public to play a role in dementia research, but until now there hasn't been an easy and coordinated way for people to register their interest. We're proud to be supporting *Join Dementia Research* to give people with dementia and their families the opportunity to be part of pioneering research to improve the lives of everyone affected by this heartbreaking condition."

Dr Doug Brown, Director of Research and Development at Alzheimer's Society said:

"We and others are increasing our investment in research to develop better treatments and ultimately a cure for dementia, but finding suitable volunteers to take part in these research studies is a difficult and costly task. This can slow research progress which is unacceptable given the urgent need of the hundreds of thousands of people affected by dementia.

"We're thrilled to be supporting *Join Dementia Research* as it will overcome many of these barriers and speed up the ongoing research effort. For people with an interest in dementia research, this innovative new service gives them the best possible chance of finding and

taking part in a suitable research study, empowering them to be part of the crucial search for better care today and a cure for the future.”

Current research studies range from clinical trials of new treatments to surveys identifying what works in improving the quality of life of people with dementia.

-Ends –

For film and interview opportunities with case studies and researchers recruiting to studies using *Join Dementia Research*, please contact

Laura Phipps, Press Office (Alzheimer's Research UK): 0300 111 5 666/ mobile: 07500803936.

Notes to Editors

*New poll figures quoted are from YouGov Plc. Total sample size was 2,227 adults and fieldwork was undertaken between 29-30 January 2015. The survey was carried out online. The figures have been weighted and are representative of all UK adults (aged 18+). The survey was commissioned by Alzheimer's Research UK.

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

The service was initially trialled in in North London trusts for six months. There are currently 1,800 registrants, 29 studies, and 82 institutes using the service.

Challenge on Dementia' is the Prime Minister's programme launched in 2012 to deliver improvements in dementia care and research by 2015.

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.

Small Business Research Initiative for Healthcare (SBRI Healthcare)

Source: <http://www.sbrihealthcare.co.uk>

SBRI Healthcare is an NHS England initiative, championed by the newly formed Academic Health Science Networks (AHSNs), who aim to promote UK economic growth whilst addressing unmet health needs and enhancing the take up of known best practice.

UCL Partners

Source: <http://www.uclpartners.com>

UCL Partners is an Academic Health Sciences Partnership whose purpose is to translate cutting-edge research and innovation into measureable health and wealth gains for patients and populations - in London, across the UK and globally.

For further information contact:

Laura Phipps, Press Office (Alzheimer's Research UK): 0300 111 5 666/ mobile: 07500803936

Ian Preston, Press Office: (Alzheimer's Society): 08450 744 395

Email: press.jdr@nihr.ac.uk