

NEWS RELEASE

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Wales to launch ground-breaking dementia research service

A nationwide online and telephone service that helps people to take part in dementia research studies launches in Wales today (2/7/15). Join Dementia Research promises to accelerate the pace of dementia research in Wales by allowing people with and without dementia to register their interest in studies, and helping researchers find the right participants at the right time.

Mark Drakeford, Welsh Minister for Health and Social Services will make the announcement during a visit to the Wales Dementia Services Development Centre (DSDC) in Bangor.

Professor Drakeford said:

“Welsh universities and health boards are collaborating in world-class dementia research and I hope that by working with people living with dementia and other volunteers, we can gain a better understanding of this condition.

“Join Dementia Research is a great step forward as we work to make Wales a more dementia-friendly nation. I want to encourage people to consider volunteering for this important work”.

Dementia currently affects 850,000 people in the UK and over 45,000 of those are from Wales. The impact of dementia is however far greater, 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. Join Dementia Research will boost research participation by connecting people interested in research to suitable dementia studies across Wales and other parts of the UK, 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.

Join Dementia Research is a collaboration between the National Institute for Health Research (NIHR), Alzheimer's Research UK, Alzheimer's Society and Alzheimer Scotland. Since its launch in England and Scotland in February, over 7500 people have registered their interest in research studies. Of those, more than 1300 have already been enrolled into research.

Bangor University's Dementia Services Development Centre (DSDC), has been leading the way on facilitating the rollout of Join Dementia Research across Wales. Professor Bob Woods, Director at the centre explains:

“Join Dementia Research is a brilliant way of bringing together people who are interested in taking part in research with the outstanding research teams we have in Wales. Our projects on understanding dementia and improving dementia care are already benefitting from the service in England, so we are sure it will make a big difference in Wales too.”

One of the studies recruiting for volunteers in Wales is called AD Genetics, which is looking into how certain genes affect the likelihood of developing Alzheimer's disease, particularly young-onset. Volunteers who are recruited to the study will be visited by a nurse and asked to complete a short interview and memory test.

Professor Julie Williams, from Cardiff University, is conducting this research and using Join Dementia Research to recruit volunteers. She said:

"Our research over the last 20 years has been made possible by thousands of people volunteering to be part of our international studies. With this help we have identified over 20 genes that contribute to the development of Alzheimer's disease, and have given us ideas for new therapies to prevent and treat Alzheimer's disease. If we had had access to a resource like Join Dementia Research we could have done our research in half the time. This will make an enormous difference to the success of future studies focusing on understanding the causes and providing treatments for early onset dementia. I applaud all those involved in setting up this venture."

Chris Roberts, 54 from Rhuddlan in North Wales, is living with dementia. He said:

"After a diagnosis of dementia your whole family also receive the diagnosis, it's a team effort. What we then need is hope; this is what research gives us. That's why it's so important for people to be aware and to know that research is taking place. As well as the people living with dementia we also need people with healthy brains. Together we can make a difference, please be a part of my team, and 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 Scotland (0808 8-8 3000), 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.

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, with the Welsh government contributing to many of these research programmes.

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

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