

## NEWS RELEASE

**EMBARGO – Wednesday 23 September 2015 (00.01)**

### **Northern Ireland to boost participation in dementia research through ground-breaking new service**

A nationwide online and telephone service that helps people to take part in dementia research studies launches in Northern Ireland today (23/09/15); during World Alzheimer's Month. Join Dementia Research promises to accelerate the pace of dementia research in Northern Ireland by allowing people with and without dementia to register their interest in studies, and helping researchers find the right participants at the right time.

Northern Ireland's Chief Medical Officer, Dr Michael McBride, said:

"Northern Ireland participates in world-class dementia research through the work of the Northern Ireland Clinical Research Network and the programme of research in Dementia Care the Department has commissioned through the HSC R&D Division of the Public Health Agency, along with our funding partners, The Atlantic Philanthropies. We need people to take part in these studies to improve the future care of people with dementia. I am delighted to support this initiative and would encourage those living with dementia and their carers, as well as healthy volunteers, to sign up to Join Dementia Research."

Dementia currently affects 850,000 people in the UK and almost 20,000 of those are in Northern Ireland. However, the wider impact of dementia is far greater, with 25 million of the UK population having a close friend or family member affected.

A recent 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 this barrier 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 only around 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 Northern Ireland 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. Launched in England and Scotland in February and Wales in July, over 11,000 people have registered their interest in research studies through the service. Of those, more than 1,600 have already been enrolled into research.

Health and Social Care, Northern Ireland are supporting the rollout of Join Dementia Research across Northern Ireland. Eleanor Ross, Public Health Agency, who co-chairs the Northern Ireland Dementia Strategy Implementation Group with Seamus McErlean, Health and Social Care Board, said:

"Join Dementia Research has seen success in connecting volunteers to dementia research studies in England. We would like to emulate this success in Northern Ireland, giving people with dementia and their carers opportunities to take part in critical research into the condition".

One of the studies recruiting for volunteers in Northern Ireland is called AFFECT, which is testing whether a commonly used treatment for high blood pressure can double up as a treatment for people with vascular dementia. Volunteers who are recruited to the study will take the drug or a placebo pill for a year and undergo memory tests and two brain scans to monitor their progress.

Professor Peter Passmore, from Queen's University Belfast, is conducting this research and using Join Dementia Research to recruit volunteers. He said:

"I am delighted that the Join Dementia Research initiative is now to be available in N Ireland. Dementia of whatever type, is caused by neurodegenerative diseases and at present there is no cure. There is a need for research into a great number of aspects of this condition. This will involve studies in people with dementia, their carers and also comparative studies with people who are not affected by any memory loss.

For over 20 years I have been involved with research into this condition and the advances in our understanding of the diseases involved has improved significantly. Local people, with and without dementia have been very good in terms of their participation in our studies. Join Dementia Research will enable people to sign up to facilitate further research and from the researcher aspect this will greatly enhance our ability to recruit people and further expand our understanding of all aspects of dementia."

Gordon Kennedy, from Belfast, who cared for his wife with dementia, said:

"During her illness, I supported my wife, Phyllis, through her participation in several clinical trials at Queen's University, under the supervision of Peter Passmore and his team. This experience has led to my involvement as a Research Volunteer with the Alzheimer's Society for the past 12 years.

Getting involved in research is so important to getting a clearer understanding of the condition and the devastating impact it can have on families. I would definitely encourage others to get involved too."

The [joindementiaresearch.nihr.ac.uk](http://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.

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For film and interview opportunities with case studies and researchers, please contact:

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Notes to Editors

\*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 officially launched in England and Scotland in February 2015 and Wales in July 2015. There are currently over 11,000 registrants and over 40 studies.

#### 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.

## About The Atlantic Philanthropies

The Atlantic Philanthropies are dedicated to bringing about lasting changes in the lives of disadvantaged and vulnerable people. Atlantic Philanthropies is a limited life foundation focused on 4 critical social issues: Ageing, Children & Youth, Population Health and Reconciliation & Human Rights. Programmes funded by Atlantic operate in Australia, Bermuda, Northern Ireland, Republic of Ireland, South Africa, The United States and Viet Nam. To learn more, please visit [www.atlanticphilanthropies.org.uk](http://www.atlanticphilanthropies.org.uk).

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