

Join dementia research: match-making

CRN: North Thames and CRN: North West London have been evaluating a new, soon to be nationwide service, which will make it easier for people to register their interest in taking part in dementia research and match people to suitable studies across the country.

The 'Join dementia research' (JDR) service was established by CRN: Dementias and neurodegeneration (DeNDRoN), in partnership with Alzheimer's Research UK and the Alzheimer's Society. By expanding the pool of interested research participants, it will vastly improve the speed of study delivery, help meet the Prime Minister's 'Challenge on Dementia', and ultimately support advances in treatment.

CRN: North Thames was chosen to pilot the scheme. One of the local Trusts, North East London Foundation Trust (NELFT), had already been recording whether patients from their Memory Services were interested in participating in research. This work was led by Consultant Old Age Psychiatrist, Dr. Joanne Rodda, who has always been keen to incorporate research into day-to-day clinical practice:

"With our local register we could put together a list of interested participants at the touch of a button, and 'Join dementia research' does that on a national scale. I think it's something that we can really offer patients as a positive thing.

"One thing people might worry about is [who gets] access to their information. So I think it's really important that we make sure that people are reassured that their information is being looked after very carefully, and that it will only be seen by people approved to access it for an approved research study."

'Join dementia research' is operating via a modern and easy-to-use online portal (www.joindementiaresearch.nihr.ac.uk) with support provided via two charity helpline numbers. The goal is to increase the numbers of potential research participants and to recruit them more quickly, at the same time as informing volunteers of ongoing research opportunities.

Tom Freeth is a Clinical Research Officer for CRN: North Thames based at Barnet Enfield Haringey Mental Health Trust. He supports and coordinates dementia research in three Memory Services, and has prior experience with patient registers:

"Although we have not historically run a lot of research studies, since we set up our own register we have become much more successful. We have run a few studies [here] and also, more importantly, actually recruited to other studies within the region, adding to the overall recruitment figures for North Thames."

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This local success story has been replicated with the launch of 'Join dementia research' – over 250 volunteers have already signed up to the register within the CRN: North Thames and CRN: North West London areas, ready to be matched to suitable studies. Across the country a further 1,200 people have already registered. The potential benefits of expanding this localised service are not lost on Tom:

"At the moment the research registers are within Memory Services or [Local] Clinical Research Networks, where members of the public can't easily access them... They have to go through the usual channels of getting a diagnosis, going to the Memory Service

and then asking about research. Whereas, because the JDR website is public-facing, it encourages members of the public - who may or may not have a diagnosis - to register."

Tom highlights one advantage of 'Join dementia research' as reduced time spent inputting data. Volunteers sign up themselves or someone else (providing they have their consent). By completing an online application form they can even express their preferences for a particular study.

"It's a two-way match-making process," says Tom. "The service is providing information and the opportunity to take part in research for volunteers. And for researchers, it's a way of finding interested, participants for both current and future studies. This helps [to assess] feasibility of future studies and to steer research where it's needed."

'Join dementia research' is helped by a national group of champions; people living with dementia and carers who have used the service or have been deeply involved in its set-up. They have been promoting the benefits of registering.

Doug Lewins, a retired civil servant who was diagnosed with Parkinson's disease six years ago. He found the experience he found traumatic and was motivated to get involved in promoting the importance of research:

"The reason I'm championing the new national service is that I'm a firm believer that what we want - those of us with long-term conditions - is better quality of life on a day-to-day basis. On a longer-term basis [we want] something that would either prevent or would cure the conditions that we have.



volunteers with research

"The biggest impact, in my mind, will be the increase in research. I'm convinced that if the recruitment procedure is made easier then we will see studies that run to time, freeing up those who are involved in a particular study to take on their next study."

Doug also believes those registered with 'Join dementia research' will directly benefit:

"An activity like research is a way of keeping our eye on the ball, and indeed giving us a good feeling about ourselves. With most long-term conditions, that is very important."

Lead researcher, Dr Paul Edison, has used the service. The aim of his study is to detect brain changes and brain inflammation in people with mild cognitive impairment, which could progress to Alzheimer's disease. He says:

"One of the biggest advantages of this new service is that it is often difficult to find the right people for a particular study. Most of the time, we see people at our memory clinics, however, finding the eligible patients who satisfy the criteria and are willing to participate in different studies is a challenge... When a research study is listed on 'Join dementia research', researchers have the ability to add specific criteria for their study, and then match the patients with this. I can see enormous potential for studies like ours."

After the success in CRN: North Thames and CRN: North West London, and with encouraging signs from other regions, the service will be launched nationally in January 2015.

Goals Exceeded in Thames Valley and South Midlands

CRN: Thames Valley and South Midlands proudly reported beating the targets set by the 'Challenge on Dementia'. Approximately 18 percent of people with dementia in Oxfordshire have participated in a dementia study, compared with 10 percent and five percent in previous years – and above the 10 percent target set by the Prime Minister.

Coordinating dementia research for the area is Helen Collins, Research Delivery Manager, who cites the use of a patient register as the key to their success.

"To date, over 1,100 people have agreed to be on our Research Interest List in Oxfordshire. This allows us to immediately contact a large number of people who meet the inclusion criteria for studies, and helps us deliver studies on time.

Linking our local register to 'Join dementia research' will further enhance its use, by making it easier to sign up people and link to studies running in other areas of the country."

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