

MEMORY CLINIC MAILING: THE BEST WAY TO SPREAD AWARENESS ABOUT JOIN DEMENTIA RESEARCH

Fylde Coast Memory Assessment Service wrote to everyone who received a diagnosis within the past 12 months to offer them the opportunity to engage in dementia research by registering on Join Dementia Research as part of a new initiative piloted by Fylde and Wyre Coast Clinical Commissioning Group (CCG). There was a 5% uptake, with more people signing up to Join Dementia Research during the first 3 months following the initiative than during the past year.

Engaging in dementia research empowers people living with dementia, who say it offers them hope and the chance to make a positive contribution. However, many people are uncertain about how to participate in research if they are not offered support to do this. Join Dementia Research is a UK-wide service that makes it easy for people to take part in research in the NHS and beyond, by matching registered volunteers with local research study teams. Once matched, volunteers can decide if they wish to participate in the research study, which can vary from drug trials to online activities to lifestyle changes to completing a questionnaire. A new initiative piloted by Fylde and Wyre Coast CCG has revealed a successful approach to recruiting volunteers to Join Dementia Research.

**"This was one
of the most
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**Laura Barnes
Service Manager,
Fylde Coast
Community Services**



Yvette Griffin and Laura Barnes, led this initiative at Fylde Coast Memory Assessment Service.

The initiative was led by Yvette Griffin (Team Manager at Fylde Memory Assessment Service) and Laura Barnes (Service Manager at Fylde Coast Community Services), who are both part of Lancashire Care NHS Foundation Trust.

Setting up the initiative

Fylde Coast Memory Assessment Service has always supported their patients to have the opportunity to access research. According to Yvette, "Join Dementia Research made research opportunities in the local area (and across the country) more accessible to their patients and visible to healthcare professionals." However, she was surprised by the data showing that more people in the area had not signed up to Join Dementia Research.

So, the team at Fylde Coast Memory Assessment Service pledged to provide information about Join Dementia Research through all the parts of a patient's journey - from pre-assessment and initial assessment, to the point of diagnosis, and through post-diagnostic care. They continue to do this by including a leaflet with initial appointment letters and having conversations in the clinic. Earlier in 2018, however, they also mailed out information about Join Dementia Research to patients who had been diagnosed during the prior 12 months.

The mailing list was created using data in manual diagnostic reports that were collated monthly over a 12-month period. An administrator went through the list monthly to identify patients who were not accepting of their diagnosis or had forgotten they had been diagnosed. When preparing the final mailing list, the administrator also checked the appropriate systems to identify if the patient was deceased or had moved to a different address.

The letter that was mailed out was drafted by Yvette and Laura, in consultation with a multidisciplinary team, which consisted of a consultant psychiatrist and two local Join Dementia Research champions. The letter provided patients with the opportunity to opt-in to find out more information about Join Dementia Research and provided a phone number of a dedicated person at the Memory Clinic (i.e., a local Join Dementia Research champion) who could provide more information or help them complete the included registration form. Information about directly signing up to Join Dementia Research, either online or via a telephone call to a Charity partner, was also included in the letter.

Once cleared with governance, the team stuffed the envelopes themselves and sent out the letters via post to 800 patients in total.

Results of the initiative

By November 2018, a total of 43 people had registered on Join Dementia Research on the back of this initiative (i.e., an approximate 5% uptake). This does not account for people who would have directly registered online after receiving the information. It is also important to note that registrations from this initiative are continuing to trickle in (and from prior experience continues for up to 12 months following similar initiatives).

Further, it must be noted that more people had signed up to Join Dementia Research within the first three months since the mailing, compared to the total number of Join Dementia Research registrations in the Fylde and Wyre Coast CCG in 2017 (20 registrations). This initiative also placed Fylde and Wyre Coast CCG in the top 10 CCGs in England in terms of the % of local people with dementia registered on Join Dementia Research (from 90th place to 8th place in four months).

See the following brief news item for more information: <http://nhs.joindementiaresearch.nihr.ac.uk/1892/nhs-fylde-wyre-breaks-top-10-ccg-people-dementia-join-dementia-research/>

Fylde and Wyre Coast CCG are now well on their way to meeting the following objective of the Government's Dementia 2020 challenge:

Every newly diagnosed person with dementia and their carer will receive information on what research opportunities are available and how they can access these through Join Dementia Research.

Lessons Learned

Laura highlighted that the initiative has been "one of the most straightforward and simplest initiatives" they have undertaken so far.

Yvette confirmed that it was a "really simple process," but highlighted that it required some administration to identify the list of patients, prepare the envelopes, and ensure the letters were posted to the correct addresses. She also stressed that it is key to make sure the whole team are aware the initiative is taking place so that they can help field incoming calls appropriately.

Laura and Yvette are now preparing to repeat the same initiative at more frequent intervals (i.e. quarterly instead of annually). Jill Simpson, Assistant Research Delivery Manager for the North West Coast Clinical Research Network, and Christine Menzies, Patient and Public Involvement and Engagement Manager at North Thames Clinical Research Network, are also hoping to replicate this initiative at memory clinics in other regions.

TOP TIPS

- Ensure you are working within the guidelines and principles of general data protection regulations.
- Include a registration form with the letter.
- Focus on one initiative that is likely to have the biggest impact.
- If possible, offer the name, number, and available hours of a local Join Dementia Research champion who can be contacted if people have any questions or queries about Join Dementia Research and the registration process.

To find out more ways to promote Join Dementia Research, please visit

<https://nhs.joindementiaresearch.nihr.ac.uk>