

SUPPORTING PATIENTS TO COMPLETE JOIN DEMENTIA RESEARCH REGISTRATION FORMS

Lancashire Care NHS Foundation Trust have become the first to achieve the Dementia 2020 Challenge objective, by registering 25% of people who were newly diagnosed with dementia in January 2019 on Join Dementia Research. This is due to Memory Clinic staff, led by Yvette Griffin (Team Manager at Fylde Coast Memory Assessment Service) and Laura Barnes (Service Manager at Fylde Coast Community Services), supporting their patients to complete Join Dementia Research registration forms in clinic. This initiative alongside sending out regular letters has proven to be one of the most effective ways in reaching patients.

Since April 2018 the Trust has been working with the NIHR Office of the National Director for Dementia Research, as a participant in the Embedding Research in Care (ERICA) Project.

"Service changes over the past few years has led to us having less contact with people. So we have encouraged staff to think that by joining dementia research patients have another avenue from which they can get support."

Laura Barnes
Service Manager,
Fylde Coast Community Services



Yvette Griffin and Laura Barnes, led this initiative at Lancashire Care NHS Foundation Trust

The initiative

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.

Memory Services at Lancashire Care NHS Foundation Trust have always supported their patients to have the opportunity to access research through Join Dementia Research – 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. They include a leaflet about Join Dementia Research with initial appointment letters and encourage staff to have a conversation within the clinic. They also recently sent out a letter to everyone who was diagnosed with dementia within the past year, which resulted in more people registering on Join Dementia Research within the first three months following the initiative, compared to the prior year. You can access the full mailings case study using the following link: http://nhs.joindementiaresearch.nihr.ac.uk/wp-content/uploads/CaseStudy_Memory-Clinic-Mailing.pdf

Now, the Memory Services team are taking it one step further and helping interested patients complete the Join Dementia Research registration forms in the clinic as part as their normal care practice – having the forms completed there and then, in clinic, alongside other paperwork that patients routinely complete. There is no pressure on the patient to register in the clinic, but offering them the support to complete and then post the forms takes the onus off on someone with a diagnosis who is interested in taking part in dementia research. Once the forms are completed, the staff collect them, check the information, and centrally post off to Alzheimer's Research UK for processing.

Setting up the Initiative

Initially, Laura and Yvette had to overcome the challenge of getting all staff (including admin staff, patient dementia advisors, medics, nurses, psychologists, and support workers) at the Memory Service on board with this initiative. However, Laura shared the following when they introduced the initiative in their team meeting: "Service changes over the past few years has led to us having less contact with people. So we have encouraged staff to think that by joining dementia research patients have another avenue from which they can get support."

Discussed, reinforced and supported at fortnightly team meetings, staff were encouraged and supporting and trained in how to approach the topic and practical aspects, such as completing the application forms and how to answer likely questions (JDR FAQs and standard materials being used to support). Staff are encouraged to share only as much as there is on the Join Dementia Research leaflet and are given opportunities to raise any issues they face with the management team.

Finally, Laura and Yvette have started an internal league table to showcase their appreciation of staff who supported this initiative (particularly those who found the task daunting).

Results of the Initiative

Since providing staff with the confidence to have conversations about dementia research as best practice and supporting interested patients to complete the registration forms, there were 18 people with dementia (25% of those who were newly diagnosed) who registered on Join Dementia Research in Fylde and Wyre Coast Clinical Commissioning Group (CCG) in January 2019. This means that Fylde and Wyre Coast CCG are the first CCG to achieve the objective set by the Dementia 2020 Challenge.

Measurement of uptake has been helped by using special 'coded application forms' so that recording of where they come from can be counted.

A more unexpected result was that the friendly in-house competition has driven adoption of new behaviours - some staff who were apprehensive at first now find the practice of offering research options to their patients quite "normal." The staff also appreciate the fact that for someone receiving a diagnosis, "signing up to Join Dementia Research gives them another focus and some hope."

You can listen to the complete audio recording about the initiative using the following link: <https://soundcloud.com/user-115269581/lancashire-care-nhs-foundation-trust-memory-clinic-erica-project>

TOP TIPS

- Each person registering on Join Dementia Research is asked if they are interested in research, and then asked to complete the form in clinic.
- For people living with dementia, ensure the registration forms are completed, where possible, by the volunteer or representative of the volunteer themselves. A representative is someone who knows the volunteer well, sees them often and would be willing and able to attend research studies with the volunteer - ideally a partner, relative or close friend. If the volunteer is unable to give consent, the representative should be able to give consent on their behalf if they hold Power of Attorney for Health and Welfare.
- Staff can complete the forms for the patient, and explain the process, what will happen, and help with complex questions – the patient then reads the consent information and signs the form.
- Some friendly in-house competition can drive adoption of new behaviours.

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

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

