

SIMPLIFYING ENGAGEMENT IN DEMENTIA RESEARCH IN MENTAL HEALTH TRUSTS AND COMMUNITY SETTINGS

In 2018, the Clinical Commissioning Group (CCG) in Leeds registered more people with dementia compared to any other CCG in the UK. Here, Holly Taylor, a Research Assistant at Leeds and York Partnership NHS Foundation Trust, shares how Leeds CCG achieved this.

The prime minister's challenge on dementia called for 25% of people with dementia to be registered on Join Dementia Research by 2020. Volunteer registrations to the service have shown an upward trend increasing month on month however many of these newly registered volunteers do not have a diagnosis of dementia.

Only 18% of total volunteers signed up to JDR had a diagnosis of dementia in the Leeds Clinical Commissioning Group (CCG) area at the beginning of 2018. However, by the end of 2018 Leeds had registered more people with dementia compared to any other CCG. This represented a 96% increase in sign-ups of volunteers with dementia within Leeds. This placed Leeds in the top 20 CCG regions in the country with regards to % of volunteers with dementia registered, compared to total number of people with dementia living in the region. The main source of these volunteer registrations was cited as memory clinics and GP practices.



Emma (Research Assistant) and Alicia (Clinical Studies Officer) with Thunder the Therapy dog at the *Tea Cosy Café*, Rothwell.



Holly Taylor, Research Assistant,
Leeds and York Partnership NHS Foundation Trust

How did this initiative start?

In an effort to increase the number of people registered on Join Dementia Research, Leeds and York Partnership Foundation Trust (LYPFT) research team worked hard to increase in engagement in dementia through:

1. Outreach work in community settings across the city.
2. Simplifying the process of engaging with dementia research in our NHS trust memory services.

Community Engagement

At the start of 2018 LYPFT researchers visited 15 memory cafes throughout the city to spread the word about Join Dementia Research. We joined people in their local communities for a cup of tea and coffee whilst having conversations about research. We spoke to people with dementia, their families and community volunteers about the benefits of research and how they could get involved via Join Dementia Research. We supported people to sign up at the time and for others, left them with leaflets and information on the ways they could join the service if they were interested.

We supported the NIHR by representing Join Dementia Research at other community events including a Research Café held alongside the 'Every Third Minute' tour by West Yorkshire Playhouse at Seacroft Grange Care home. We also attended Leeds Irish Centre who hosted a dementia event in an effort to engage this community in dementia and research conversations.

Increasing Trust Engagement in Dementia Research

In the latter part of the year (June 2018) new NICE guidelines for people with dementia were released stating all people with dementia should be provided with information on research studies they could take part in. This national backing prompted us to review the ways in which we work with our memory services to communicate the trusts dementia research opportunities.

Creating a research presence

Our aim as a Trust research team is to ensure that research is embedded as part of routine clinical care. One simple strategy we have implemented is to install research specific noticeboards in waiting areas of our trust sites. This acts as a resource for both service users and clinical staff and means research has a presence within clinical areas. It is clear and simple and contains our current recruiting studies, information about Join Dementia Research, and ways to get in touch.

Simplifying research conversations

A barrier to clinicians talking about research with their service users is having to keep in mind the breadth of dementia research studies we have recruiting in the trust. We want clinicians to feel involved in the trusts dementia research process but without having to remember the finite details of projects including study specific inclusion/exclusion criteria. We wanted to simplify the process of clinicians talking about research with their service users. Similarly to other trusts we requested clinicians ask two simple questions to every service user they see.

We created A5 diary size versions of these 'research referral forms' as a prompt to ask the two simple questions at every contact. Alongside this we have also created a one-page document containing brief summaries of all our NIHR recruiting dementia research projects. This is updated and circulated to clinicians on a monthly basis to keep them informed of our current research projects. NHS staff can also learn more about Join Dementia Research by completing the LEARN tool online:

<http://learn.joindementiaresearch.nihr.ac.uk>

Keeping research on the agenda

The trust held a Memory Services Communications Meeting monthly, bringing together memory service staff from across the city together to communicate and discuss service wide issues. Holly attended these meetings every other month so that research was kept on the agenda. She also attended the monthly Senior Managers meeting for the same purpose.

Doing this has a number of benefits including the following:

1. Developing closer working relationships between the research team and memory service.
2. Being embedded as part of the clinical teams ensured research became a part the memory service 'usual business' within the memory service.
3. Keeping the service up to date on current projects including updates on study progress and disseminating research outcomes.
4. Keeping up to date on changes within our memory services. This helps us in identifying clinically relevant studies the trust can take on and where they will fit in to our clinical services.

Summary

As well as communicating information about research it was important to communicate the value of research to clinical staff. Implementing simple strategies and supporting staff to talk about research with their patients is of no use if clinicians do not see the patient benefits. If clinicians do not understand the implications of research on patient care they will not be motivated to talk about research with their service users. The Join Dementia Research video 'Why you should support dementia research?' is a good example of the service user perspective on the importance of dementia research. Creating a research culture within NHS trusts is an ongoing process. We wanted to simplify the process of memory service engagement in dementia research and developed a number of ways to try and integrate research within clinical teams and make it part of a patients care pathway.

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Holly Taylor
Research Assistant,
Leeds and York Partnership NHS
Foundation Trust

Impact of this initiative

- In 2018 Leeds registered more people with dementia than any other CCG region.
- There has been an increase in the number of clinician referrals since the engagement process.
- Research staff supported 31 people to sign up to JDR from attendance at memory cafes. 10 of those people had a diagnosis of dementia.
- Community organisations we have engaged with in Leeds have an increased awareness of Join Dementia Research. They have put information on Join Dementia Research on their websites, information leaflets and newsletters.

Lessons learned

- Clinical services are subject to change.- LYPFT is currently undergoing a community services redesign. This will have an impact on the dementia care pathway for patients and the staff working in services.
- To ensure the initiative maintains its importance in new services, we will have to be flexible and change our approach to mirror the changes in services

Next Steps

- We will continue to find the right places and the right meetings for us to communicate our message.
- We are soon moving to a new electronic patient record system, which should make the referral process easier.
- We will continue to focus on sharing the positive impact of research. We have created a video in partnership with the NIHR sharing stories of participants involved in our trust research. This will be shared with clinicians through a variety of means.
- We will encourage healthcare professionals to complete the online LEARN tool:
<https://learn.joindementiaresearch.nihr.ac.uk/>

TOP TIPS

- Trying to create a research culture is an ongoing and lengthy process but it is important to be persistent.
- Develop a personal approach to research engagement and an individualised approach for different staff groups, i.e., memory nurses vs consultants.
- Find the right meetings to attend to communicate your message.

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

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



Crystal (Research Assistant) with Iria (Activity coordinator) at the *Hug in a mug* memory café Seacroft Grange Care Village