

AIMING TO LEAVE NO STONE UNTURNED: TEES, ESK & WEAR VALLEYS NHS TRUST ARE ON A QUEST TO LET PEOPLE WITH DEMENTIA KNOW ABOUT RESEARCH

Tees, Esk & Wear Valleys (TEWV) NHS Foundation Trust have shown determined commitment to letting people living with dementia know about research and how they can take part in studies. Lauren Roberts, Research Assistant at TEWV Trust, shares the various approaches that have been taken to meet this goal.

Research Champions Organisations

The research team at TEWV have been working with Corinne Walsh, the Project Lead for North of Tees Dementia Collaborative. The North of Tees Dementia Collaborative strives to increase collaboration between organisations that work with people with dementia and make the best use of available resources to improve the care delivered to people affected by the condition and their families.

Meeting together, the research team and Corinne realised they had the same objective of increasing the amount of people who are taking part in research that is being conducted by the Trust.

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Corinne Walsh
Project Lead,
North of Tees Dementia Collaborative



Lauren Roberts, Research Assistant,
Tees, Esk & Wear Valleys NHS Foundation Trust

"TEWV came to me at just the right time. At the Collaborative we are always looking for ways to work together to benefit those living with dementia in North Tees. Being able to offer them a chance to register their interest in research supports our work in this way," Corinne shared.

They arranged a research event where all the Dementia Collaborative members were invited and asked if they would be interested in becoming a Research Champion Organisation. Being a Research Champion Organisation means that these organisations help promote new dementia research studies in the Trust, in addition to making people aware of Join Dementia Research and helping them sign up if they are interested. Join Dementia Research is a nationwide service allowing people with and without dementia to register their interest in participating in studies. Members of the Dementia Collaborative are well suited to helping promote the service as a lot of these organisations are in daily contact with people living with dementia. Lauren is currently visiting all the organisations that have expressed interest in becoming a Research Champion Organisation to give them some training - telling them more about the Join Dementia Research service and what studies are currently open in their region. Lauren is pleased that she is already seeing the benefit, as one of the research studies recruiting in the Trust saw 50% of the people who took part in the study come through Join Dementia Research and one of the trained Research Champion Organisations. Katie from The Bridge, which is based in Hartlepool, shared the following: "We were delighted to become a Research Champion Organisation - anything we can offer our membership is of great benefit, and research gives hope."

Feedback from our service users has also been positive, with one user stating that “it has been great to learn about opportunities to become involved in local and national research.”

This success has also been noted by other regions, with Clinical Research Network at Yorkshire and Humber already keen to follow suit. Lauren has met with Clive Nicholson, a Senior Research Nurse from the Clinical Research Network at Yorkshire and Humber, so they can learn and replicate this initiative in their region.

Lauren is well aware of the importance of keeping in regular contact with these Dementia Collaborative members. “It is key I keep in touch with all these new Champions to keep them engaged, and see if they need new materials. I also like to see how many people they think they have helped sign up to Join Dementia Research so I can gauge impact on numbers,” she said.

Engaging Trust Staff

In TEWV, most people with memory problems are referred from their GPs to a Memory Clinic, which assess the cause of their difficulties and if they might have dementia. It is therefore hugely significant to get Memory Clinic staff on board, so that they are able to refer people to Join Dementia Research and research studies, where appropriate.

Lauren is currently looking to meet with all the Memory Clinic teams in the Trust to let them know about the two-question referral process the research team offer. This process involves Memory Clinic staff asking their patients the following:

1. Are you interested in research?
2. Would you like us to pass your contact details onto the research team?

“People prefer to talk about taking part in research in an environment where they feel comfortable. Usually for any appointment, people with dementia have to go out of their way to visit a hospital. It’s a lot easier if somebody comes out to see them. They really appreciate it.”

Lauren Roberts,
Research Assistant,
Tees, Esk & Wear Valley NHS Trust



Memory Clinic Team team at Community Mental Health Services for Older People, Stockton-on-Tees, who have reached 100 referrals to research

These referrals are then sent onto Lauren, either via the Electronic Recording System with patients’ case notes or email. Since Lauren is aware each Memory Clinic works differently, she ensures that she checks with each one about which option would work best for them.

From there, each patient is contacted and asked whether they would like a home visit to discuss research or a call from Alzheimer’s Society (one of Join Dementia Research’s charity partners). Lauren stressed the importance of offering home visits. “People prefer to talk about taking part in research in an environment where they feel comfortable. Usually for any appointment, people with dementia have to go out of their way to visit a hospital. It’s a lot easier if somebody comes out to see them. They really appreciate it,” she highlighted.

These ‘referrals to research’ can happen at different points along the care pathway. For example, if the referral comes from a Consultant Old Age Psychiatrist, it usually happens at the point of someone being diagnosed with dementia. However, if it comes from a support worker or a member of the Community Mental Health team, then it is more likely that the patient would receive this referral at the six-week medication review or the six-monthly or yearly review. Therefore, it is critical that staff at all stages of the Trust are engaged and aware of how they can let patients know about Join Dementia Research.

To encourage staff, teams also receive Certificates of Appreciation when they hit a certain number of referrals to research. The Memory Clinic team at Stockton-on-Tees, who were the first to refer 100 patients to research, shared the following: “We ask and give patients lots of information at review appointments. Having the two prompt questions makes it quick and easy for patients to understand what we are asking.”



Pharmacy hosting
Join Dementia Research kiosk

Pharmacy

People with Alzheimer's Disease may be prescribed medication to help aid some of the symptoms of the condition, which therefore can mean a visit to the pharmacy. Therefore, Lauren is also working with pharmacies (both chains and independent pharmacies) to encourage Join Dementia Research registration forms and leaflets be put inside dementia medication prescription packs.

Although it is still too early to assess the impact of this initiative, Lauren is pleased that pharmacists have shown interest in being involved. "I'm working with a manager of a pharmacy chain who's keen to trial this with 125 Healthy Living Pharmacies in the local area," she said.

Join Dementia Research Information Kiosks

Working with the Office of the NIHR National Director for Dementia Research, Lauren has also been scouting out pharmacies that can host a Join Dementia Research kiosk. These kiosks allow anyone to enter some basic details and select whether they would like to be contacted by email or call. They will then receive more information about Join Dementia Research (either by email or call) and have an opportunity to register their interest in participating in research by signing up to the service.

This project has proved more challenging than first thought. Although pharmacists have been willing to display the kiosk, there have been challenges with connecting to the local Wi-Fi, which means that the kiosks had to be moved around to new sites.

"It has been challenging, as I feel this is a great campaign, but it has taken a lot of time to find suitable locations with adequate Wi-Fi to run the kiosk, and enough floor space", Lauren added. Undeterred, however, Lauren is now looking for other healthcare settings, such as GP surgeries, which may be able to host a kiosk.

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Memory Cafes/Support groups

In a quest to leave no stone unturned, Lauren also reached out to community organisations in the region, such as Alzheimer's Society and Dementia Forward. Some of these organisations run Memory Cafes - which are social gatherings where people affected by memory loss and their families can meet together.

Lauren offered to go along to the groups to talk about Join Dementia Research, highlighting the opportunity to sign up to the service. In these situations, she often sees a number of people who register their interest straight away, so has found it a worthwhile endeavour.

Exploring these different avenues has been critical; "It is important to promote Join Dementia Research in multiple ways to ensure everyone is reached and knows about this opportunity to be involved in research," Lauren concluded.

Top Tips

- Use the Alzheimer's Society website (<https://www.alzheimers.org.uk/find-support-near-you>) to find help find potential Research Champion Organisations within a certain area, including those outside of Alzheimer's Society.
- Directly approach the managers of potential Research Champion Organisations to get quick results. Offer to meet them and discuss current studies that they can promote.
- When approaching pharmacies to help promote Join Dementia Research, contacting pharmacy superintendents has shown faster results. Make things as easy as possible for them to enhance the chances of their assistance with promoting Join Dementia Research.

For more information visit:
nhs.joindementiaresearch.nihr.ac.uk