

SUPPORT AT HOME - THE KEY TO SIGNING UP NEW RECRUITS

We spoke to Lauren Roberts, a Research Assistant at Tees, Esk & Wear Valley (TEWV) NHS Foundation Trust, about the different ways she's successfully recruited people affected by dementia to Join Dementia Research.

Part of Lauren Roberts' role as Research Assistant, is to promote the Join Dementia Research service and sign up as many people affected by dementia as possible. Over the past eight months, Lauren has tried and tested a number of different approaches. She believes the key to her success has been offering support to people at home, as she explains, "I arrange to meet people living with dementia and their carers in their own home, to talk it all through in more detail. They can ask me as many questions as they want, and then I do the signing-up for them. This is especially important for the people who are hard of hearing, or have poor sight - or who don't have access to a computer, or aren't computer savvy. I can help them to sign-up online."

This approach clearly makes a difference. Since bringing Lauren into post, the Trust has seen a dramatic rise in the number of people signing up to Join Dementia Research (see Fig. 1). In 2016-17, 818 people were recruited over an eight month period, whereas another area (with similar numbers of people with dementia but where they don't make home visits) recruited only 473 people during the same eight months.



The feedback from the new recruits has been very positive. For example, one person with dementia commented "This personal approach is so important - it is much better putting a face to a name". Lauren believes that "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 covers a broad area in North Yorkshire, including York and Selby. To reduce journey times and travel costs, she tries to organise all the home visits in one place on the same day, "That way I'm only going from one house to another in the same town. If I was trying to make long journeys across the county, it would be too expensive and impractical".

Home visits are now offered to every person affected by dementia who expresses an interest in signing up to 'Join Dementia Research'. But how does Lauren find these people in the first place? Over time, she has developed a number of different approaches. When she first started, Lauren searched online for all the support groups in the area and made contact with the facilitators to arrange giving a talk at one of the group's meetings. She found this was a good



way to reach a large number of people affected by dementia all at the same time. After asking questions, some of them were happy to sign up to Join Dementia Research on the spot, but many preferred to give their contact details and then organise a home visit. This is how the home visits got started.

Lauren has since streamlined the process of organising talks, as she explains “I cut out the middle man by going to the area managers instead of the facilitator of every group. The managers are able to give me blanket permission to access all their groups, so it’s easier and a lot less time consuming.”

Lauren also contacted local health professionals to ask if they would be willing to help recruit their patients to Join Dementia Research. At first, she was concerned that it would take too much time out of their consultation, and that they wouldn’t feel

confident answering the patients’ questions about research. So she worked with an advanced nurse practitioner, who is also a local research champion, to develop a more clinician-friendly approach. They developed two simple questions for health professionals to ask their patients:

(1) Would you be interested in taking part in research?

If Yes, (2) Would you be happy for me to get someone from the research team to contact you?

If the patient answers ‘yes’ to both questions, the clinician then sends Lauren the patient’s ID number to enable her to find their contact details on the Trust’s clinical notes system, and then she follows up with the individual patient. Lauren has done a lot of work to promote this simple system, attending a number of team meetings within the local memory services and community mental health teams, as well as talking to individual consultant psychiatrists and psychologists. It has been well-received and is now widely-adopted across the Trust.

By attending the clinical team meetings, Lauren was able to identify other opportunities to reach large numbers of people with dementia, “I now routinely go to the second-to-last, or the final meeting of the cognitive stimulation therapy groups. I go along and talk about Join Dementia Research, which they usually quite like, because when they are coming to end of the group, people sometimes feel that they would like to be included in something else right away. So it’s a good time to hear about research opportunities, just as that group is finishing.”

For similar reasons, Lauren has also found it helpful to speed up the process of being recruited to a research project, after people with dementia are first signed-up. “My colleague suggested that when I do the home visits, I give people an example of a study they might be eligible for, and that works really well. I can say ‘Would you like me to contact someone who can then contact you about the study?’ and it can fast track them a little bit, especially if they sign-



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up on paper, because it can take a couple of weeks for them to be logged on the system. This means people feel something is happening quickly, while it's still fresh in their minds and they are keen to get involved."

Lauren has taken some of the more common approaches to promoting the service, for example, putting leaflets, posters and information on the TV screens in GP surgeries as well as adverts in local newsletters. She's uncertain whether these outlets have been successful. She's now trying some more innovative schemes, including putting leaflets in with people's dementia medications in pharmacies, "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. We're still planning to attend an event where we can speak to all the pharmacists who might get involved. We're also thinking about having an electronic tablet device at pharmacists which displays the Join Dementia Research mini-site and allows people to put in their email address, so they can then be sent further information".

It's not always obvious which approach works the best and Lauren is thinking about ways to monitor this. She's looking at the numbers of recruits from different geographical areas to see whether there's any pattern that links to any particular activity, as she described, "With one example, we've found an organisation that delivers meals to people with

dementia and they have asked if they could put our leaflet in with their deliveries. We're only doing that in one area, so we'll be able to tell whether it makes a difference by looking at whether there are changes in the number of recruits from that particular area over the next few months". Finding out what works best and for which people, is helping Lauren to refine what she does and get the most return from her efforts.

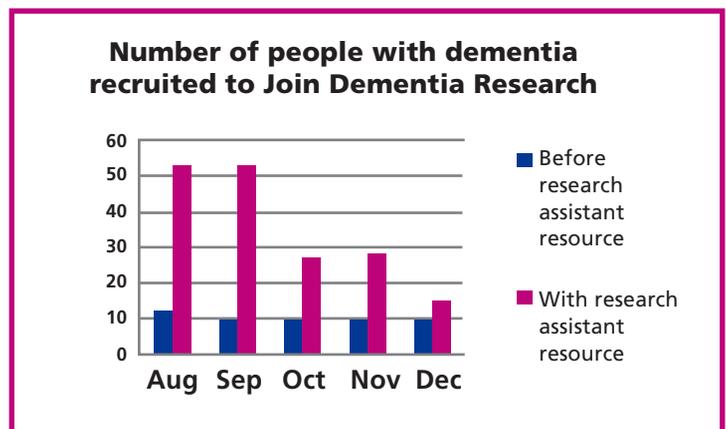


Fig. 1: The impact of Lauren's approach to recruitment to Join Dementia Research. (Blue bars are from Aug – Dec 2015, before Lauren was in post and pink bars are from Aug-Dec 2016, with Lauren in post).

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