

TAKING A FRESH LOOK AT NEW ROLES: DEVELOPING RESEARCH WITH PRIMARY CARE

Project Description

The local Clinical Research Networks face two considerable challenges in their day-to-day work. The first is how to recruit to new research studies and clinical trials opening locally and the other is how to keep abreast of the changes wrought by reforms taking place within the National Health Service. An opportunity arose in East Anglia to address both of these issues in one project within the dementias and neurodegenerative diseases research area.

With the advent of a new Primary Care Dementia Practitioner (PCDP) role, the local network seized the chance to work with them from inception to raise awareness about research with a group tasked with identifying and diagnosing memory problems in patients. In so doing, the network potentially opened a gateway to enhanced recruitment of people at a very early stage of diagnosis from a primary care setting. However, although good working relationships were built and recruitment into one locally recruiting study was boosted, the PCDP cohort did not become as firmly rooted in primary care as had been initially assumed and, as a result, fewer GP practices and patients than anticipated were identified for research purposes going forward.

A unique opportunity

Historically, the role of the general practitioner has been an important one, and due to new reforms being implemented across the National Health Service, primary care is taking on a renewed



challenge as many of the conditions and diseases once seen predominantly in secondary care move back into the community.

In order to help with this increased workload, new positions are being established across the NHS. The Government's Quality, Innovation, Productivity and Prevention (QIPP) initiative is part of this transformational programme for the NHS. Its aim is to improve the quality of care the NHS delivers whilst making substantial savings that can then be reinvested in frontline care.

One project that QIPP has invested in in the Norfolk area has been in the creation of a new Primary Care Dementia Practitioner (PCDP) role. The goal was to embed mental health nurses within groups of GP surgeries to provide a pre-assessment or triage point for people with memory problems.

This suggested that the cohort of PCDPs would come into contact with nearly all new referrals in this revised care pathway and, as such, it represented a unique opportunity to promote research and to invite patients either to join a current study or to register interest in future studies. Not only that, it also potentially opened a new mechanism to enhance the local research network's links with GP practices and to support the promotion of dementia research studies in primary care.

Fostering relationships with PCDPs

Recognising the opportunities to work together, the local research network designed a project to reach out to this new group and to provide them with ample information to give to patients who may be interested in getting involved in research.

At the start of this project there was no systematic way of identifying people with dementia in the local Trust. Finding suitable patients for dementia studies frequently involved manual searches of individual sets of paper case notes. This was both time and labour intensive and was considered to be an inefficient and expensive way to identify potential people for recruitment.

The project team fostered good relationships with the PCDPs and was invited to meetings with them from an early stage. This helped to embed the research message with them and this, in turn, got the research message to people at the often difficult early stage of diagnosis.

Juniper West, Clinical Research Nurse in East Anglia, says "We developed a leaflet. We also offered patients a 'consent for contact' register which they could sign up to and the network could then approach them if and when a study that they might be eligible for opened in the local area".

However, the leaflets did not prove to be a very successful method for recruiting patients. By the end of the project, of the 500 leaflets distributed, only 15 had been returned. But a much more successful recruitment strategy did emerge.

During the project one dementia study was actively recruiting locally. The individual Cognitive

Stimulation Therapy (iCST) study was a non-commercial, interventional study based on the successes of group CST which has been shown to improve memory and quality of life and to be cost-effective when delivered to people with mild to moderate dementia. The study investigated whether individual CST sessions delivered by the carer had similar effects on cognition and quality of life and are both practical and appropriate for people with dementia.

Within four months of site initiation, the PCDPs had increased self-referrals to over 40. Kerry Avery, one of the PCDPs, added: "It's important to capture people's imagination with research. The iCST project was a great one for us to cut our research teeth on as it was one that both carers and patients could get involved with".

Join Dementia Research allows anyone to express an interest in taking part in dementia research studies themselves, without committing themselves to research. As registrants are matched to studies, geographical location is also taken into account so potential participants can find out about research taking place locally.

Our footprint left behind

Forging good working relationships with the PCDPs made this new group consider research as an integral part of care. Thanks to the project's efforts, research was high on their agenda and provided a previously unexplored pathway to offer to newly diagnosed patients. The PCDPs also brought into studies which they felt offered their patients interventions which they saw as valuable and perhaps not otherwise available. This was particularly true for referrals into the iCST trial which predominantly captured people with vascular dementia.

The group sees patients at the beginning of the care pathway. This was useful as many new studies can be targeted at early or pre-dementia stages.

The project also had a very practical spin-off for the network. There is now an emphasis on writing better, informative literature targeted more precisely to this patient group. Kim Clipsham, Senior Research Nurse in East Anglia, says "One of the drawbacks of the leaflet that we produced was that the cost was

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around £1 per leaflet. For the number of referrals that we actually witnessed via this leaflet, the return on investment wasn't good so we're now developing a more innovative, business card-sized publication that simply has some details on it and has the website address too, should patients wish to visit the site to find out more".

Join Dementia Research materials are available free to order. Visit: news.joindementiaresearch.nihr.ac.uk/join-dementia-research-materials for more information.

Passing the learning on

One of the key learning points for the project team was to ensure that the team members are aware of and invited to meetings where new groups or roles are being established. Juniper West explains that strategy: "The PCDPs were a completely new group and, by getting a seat at the table during these critical set-up meetings, the network had a golden opportunity to work with these nurses from the start. This meant that the research message was there right from the beginning and allowed the PCDPs to feel more confident about speaking to people at an early stage of diagnosis. This really helped to raise awareness about research and to raise the profile of the network".

However, the biggest challenge that the team encountered was that, as a new group, the PCDPs had a very fluid role and, because of on-going changes to the service configuration, there was less development of research in GP practices than had been originally envisaged. Kerry Avery explains, "This was a new role that was designed to improve the educational aspect of dementia care in the Trust. Research is an important thing to be able to offer the patient. But, as the PCDPs only see patients twice – one initial meeting followed up by a second meeting where the diagnosis is discussed, there was little continuity that we could offer".



Top Tips

- Realise that, although roles and responsibilities may be subject to change, the value in relationship building and networking across the local area can be invaluable in the long run
- Recognise that an approach for consent into a research study or clinical trial may be difficult around the time of diagnosis as this can be a stressful and upsetting time for the patient
- Ensure that, wherever possible, a relevant research study or clinical trial is open to recruitment locally - Healthcare professionals can register for an account on Join Dementia Research to see what studies are recruiting locally

For more information visit:

nhs.joindementiaresearch.nihr.ac.uk