



Opening the door to primary care

Collaborating with the Primary Care
Research Network

Project Description

Working across the broader healthcare community can be fraught with difficulties because of the changing nature of the NHS and the number of stakeholders involved in decision making processes. The same is true for the clinical research networks as each is charged with recruiting patients into certain trials or from certain locations. Collaboration is key to enabling the research process and this project involved close collaboration between the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) and the Primary Care Research Network (PCRN); the clinical research network tasked with raising awareness and supporting recruitment from general practice.

New GP surgeries were identified by PCRN in conjunction with DeNDRoN and different mechanisms were used to foster effective and efficient cross-working. The project outcomes highlighted several areas for possible improvement that could be made in working together and where the two network cultures could identify strengths and weaknesses in their individual processes and procedures. Teamwork and cooperation helped DeNDRoN and PCRN to find new practices willing to be involved in research and to look forward to exciting potential collaborations with new studies in the research pipeline.



INTEGRATION



CASE STUDY

Our national health service is one that, over the past few years, has witnessed enormous change. Many diseases and conditions that historically were treated mainly in hospital settings have been moved out into the community and now sit squarely in primary care with general practitioners (GPs). With this evolving backdrop of new care pathways and management strategies, it is important that relationships with GP surgeries are fostered in order to enable the free flow of information about trials and studies from the research networks and patient identification for participation in research from primary care.



This is particularly pertinent in the field of dementia where there is a wide spectrum of patients ranging from those with mild memory impairment to those with advanced dementia. In order to examine possible recruitment from primary care, the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) launched an innovative project to explore the channels of communication open to them which would allow engagement with GPs and other healthcare team members based in primary care. By expanding the number and scope of professionals able to signpost their patients effectively and accurately towards local research projects in DeNDRoN's portfolio, the objective was, in turn, to expand the number and scope of patients willing to participate in these studies.

Project Design and Implementation

The DeNDRoN team identified three possible studies that could be flagged up to GP surgeries as exemplars of the kind of research projects adopted by the network. The first of these, the Parkinson's Monument Discovery (PD Discovery) study, is a large-scale project aiming to recruit 2000 patients with Parkinson's disease and striving to identify any genetic or other markers that may act as signals of disease progression. The second, Brains for Dementia Research, promotes brain donation to help researchers investigate dementia. And the third was the PD Exercise study which is hoping to clarify the effects of long-term exercise on the symptoms, fitness, health and wellbeing of patients with Parkinson's disease.

The next step was to work with DeNDRoN's sister network, the Primary Care Research Network (PCRN) which is tasked with supporting research in primary care. Preliminary cross-working soon identified some challenges in the cultural differences between the two networks and contrasts in the ways that DeNDRoN worked and PCRN worked. So, to simplify the process, two of the original trio of studies – the PD Discovery study and the Brains for Dementia Research programme – were omitted from the equation.

Claire Merritt, lead research nurse manager with DeNDRoN, explains the reasoning behind this decision. 'The chief investigator for PD Discovery study felt that, in hindsight, trying to recruit patients into this project from primary care may not be particularly effective. At the same time, it was also felt that the Brains for Dementia Research project was perhaps a bit too sensitive. Brain donation is a highly charged and emotive subject and we felt that invitation letters sent from the GP surgery without prior discussion was not the best way of recruiting patients.'

Working with the third project, PD Exercise, the team engaged with GP surgeries across the Thames Valley Primary Care Partnership to ask if they would be interested in becoming involved.

A series of initial meetings were held with representatives from this Primary Care Partnership and discussions focussed on how best to connect with GP surgeries and encourage them to become patient identification centres for studies currently recruiting in the area. A total of eight surgeries in Oxfordshire, Berkshire and Bedfordshire were identified through this process and the research facilitators

from PCRN sent a series of letters and flyers to the selected sites.

Impact of the Project

Although the uptake from this initiative was low, we sent out of over 100 letters sent from eight GP surgeries across the patch, however only two patients with Parkinson's opted to participate.

Claire Hall is a research nurse who worked on this initiative. 'This was one of our network's first forays into trial recruitment via primary care and we weren't quite sure what to expect. We were also uncertain as to the best channels to use to engage with GP surgeries'. She continues 'Whilst the actual number of GP practices wishing to get involved was low, the learning outcomes for us have been quite significant.'

Challenges and Learning Points

Helen Collins, the local research manager for DeNDRoN in the Thames Valley region, takes up the story. 'It was perhaps a little naïve to think that we could simply open three new studies for recruitment in primary care. GPs are already stretched providing care for their patients. In hindsight, to ask them to take on board research almost overnight wasn't going to work. But we've learned from our mistakes. In addition, this was the first time we had collaborated with our colleagues in the PCRN so finding mutually beneficial ways of working was also not something that was going to happen in the blink of an eye.'

The team has worked through the initial disappointment and has some new strategies in place for future efforts. As is often the case, some GP surgeries were more receptive than others to the initial ask. By working closely with them and with the PCRN, it may be possible to make these surgeries into 'poster boys' for other GP surgeries, championing research and their links with DeNDRoN. Moreover, with new studies coming through the pipeline, the network is looking at the ethics applications and approval processes for these trials with a view to identifying potential primary care recruitment early and establishing what is most likely to work on a study by study basis. Most importantly, though, are the key relationships that have been built both with colleagues in primary care and with the PCRN, collaborations that will give recruitment into future studies a bright new start.

Conclusion

While the original measures of success for this project were not met, the DeNDRoN team is now more aware of the opportunities that primary care may be able to afford future studies and has alerted them to possible cross-working solutions. Closer operational relationships could produce more effective communication strategies. Promotional materials should have been produced in collaboration as this may have led to a more tailored and targeted approach to the surgeries receiving the materials. This may, in the future, then increase the number of colleagues in the primary care setting that are informed, able and willing to engage with DeNDRoN.



PATIENTS IN RESEARCH

Tips

- Appreciate that cultural differences exist and that operational working practices vary between primary and secondary care and across the clinical research network landscape
- Recognise that certain clinical trials and studies may be more appropriate to a primary care setting than others
- Ensure that, wherever possible, joint input into all written and verbal communication with primary care colleagues is encouraged
- Acknowledge that additional training may be necessary to provide people new to dementia and neurodegenerative disease research with a greater understanding of the challenges facing recruitment from this diverse patient cohort
- Exploit the benefits that engaging with small numbers of GP surgeries can offer in relation to a fuller understanding of their community and in promoting a powerful word of mouth conduit to neighbouring GP practices



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