



Recruitment. Recruitment. Recruitment.

Embedding a Research Culture

Project Description

Recruitment into clinical trials and studies can be notoriously difficult. The reasons for this are complex but revolve around two main issues. There is the obvious step of engaging patients and members of the public, but then there is the more challenging task of encouraging our healthcare teams to be passionate about research.

With our healthcare system already stretched, getting individuals and teams informed and excited about involvement in the research process can be a challenge. The Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) piloted a study in the neurology department at the John Radcliffe Hospital in Oxford to investigate the best mechanisms for encouraging commitment to and enthusiasm for running research studies. Using a different approach, rather than concentrating solely on the senior consultants within the department, the DeNDRoN team worked across the spectrum of healthcare professionals. They worked with the wider multidisciplinary teams, fostering relationships with as many of the stakeholders as possible, in order to get a holistic view of who was interacting with patients and at which steps along their care pathways. Having identified the most appropriate processes and procedures, the team set about offering studies as test beds. Within six months, the initiative had captured the imagination of the healthcare teams and research is now firmly on the map across the neurology department.



INTEGRATION



CASE STUDY

It is often said that there are just three problems in running clinical trials and studies. Recruitment, recruitment and recruitment. However, issues of recruitment are not limited to getting patients involved in research. The first step to successful recruitment is often in raising awareness about research with healthcare professionals, the people who are interacting with patients on a daily basis. But how do you take on an entire healthcare system and encourage it in all its diversity to engage with and be enthused by clinical research?

The Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) quickly realised that this was not feasible. Adam Smith, programme manager with the network, says "It's about one Trust at a time. One department at a time. It's just naïve to think that we can change a culture overnight in a healthcare system as complex as our NHS so we piloted a project to investigate how we could do this in just one department."

The Thames Valley region covers a large geographical swathe of England across Oxfordshire, Bedfordshire,

Buckinghamshire, Leicestershire and Northamptonshire so the project group focussed on just one major hospital at the heart of the region – the John Radcliffe Hospital in Oxford. "The hospital historically has a very good track record of conducting pioneering research. Despite this we had varied levels of engagement with the consultant neurologists in the hospital so we looked for innovative ways to improve that and ensure that patients were consistently given the opportunity to join studies" continues Adam. "What we decided to do was to open the discussion up right across the neurology department."

Impact of the Project

By working around the multidisciplinary team involved across the neurology landscape, the team succeeded not just in including and engaging healthcare professionals but also in involving and raising awareness with patients.

Dr Binith Cheeran is one of the researchers who has benefitted from this project. "We have a named network research nurse for each new project, who handles recruitment through the RAFT database. She screens for patients who fit the profile for new studies and then contacts them to let them know. If they're interested in finding out more, she will send them all of the patient information sheets. It's this personal touch that makes all the difference.

"Thanks to this, we've now got quicker recruitment into new projects. It's more efficient and it's more accurate".

Within the first six months of this project, over 120 people had submitted their details to the RAFT database. Dr Michele Hu, one of the consultant neurologists in the hospital, explains what this figure represents: "This is 120 people who have been signposted towards RAFT through the efforts of the network team within just a few months. As this programme is rolled out, as the healthcare professionals within the John Radcliffe Hospital continue to embed the research culture with renewed vigour and as word of mouth alerts more people with Parkinson's disease to this resource, we're hoping that it will grow and grow. This, in turn, will then allow us to recruit more people into more trials and that could ultimately help us to find new treatments and care strategies for people with Parkinson's".

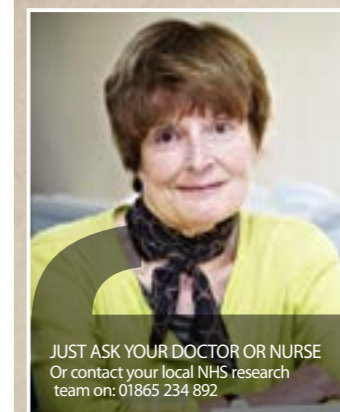
Project Design and Implementation

The department currently employs around 20 consultants but over 100 further members of staff are involved in the direct care of people with neurological disorders. The DeNDRoN team took on the challenge of engaging with all of them from the consultants to the administrative staff and the speech therapists to the wider nursing staff. Helen Collins, DeNDRoN's local research manager for the Thames Valley region takes up the story. "We decided to pilot a session to which we invited as many of the neurological multidisciplinary team as possible. The purpose of this was essentially two-fold. First, there was the important relationship building aspect. But second, we created the opportunity to discuss research and facilitated an open forum for exploring engagement, identifying any hurdles or obstacles that might be hindering this. More importantly, we wanted to find out what processes we could put in place and where we could help to get more patients into research studies on the DeNDRoN portfolio."

The team identified fifteen key stakeholder groups who refer or who could facilitate referral of patients for possible inclusion in research studies and local 'consent for contact' lists. An initial meeting was arranged at which some of these stakeholders generated proposals for how to engage effectively with all of them and a number of project objectives and timelines were formulated. In order to keep the momentum of this initial meeting, these diverse groups had dedicated project team members allocated to each individual stakeholder group. Six project team meetings were held over the following nine months to coordinate stakeholder engagement, to check on progress and to plan and agree actions going forward.

In addition, the stakeholder groups were encouraged routinely to inform patients about current studies and to signpost them to the region's 'consent for approach' database.

The Thames Valley region's Patient Register (RAFT) database for people with Parkinson's is an innovative system to capture the details of those who are interested in getting involved in local research. And it's not a laborious process. Designed to fit onto just one side of A4 paper, this 'consent to be contacted' form simply records the patient's name, age and contact details with some information on disease progression and current treatment. Once on the database, these details allow patients to be screened very easily for their suitability and possible inclusion in new research projects on the local portfolio.

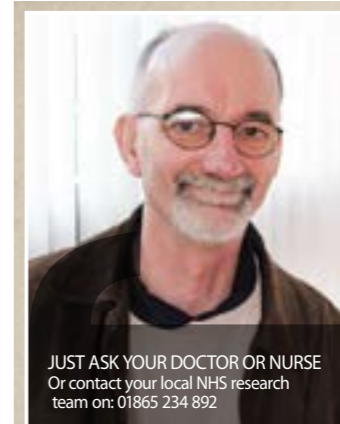


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Challenges and Learning Points

Despite the success of this project, the team is aware that there are still valuable learning outcomes from the process. The first challenge is in recognising the diverse number of stakeholders that work across the multidisciplinary team. Engaging with all of them can be resource intensive. 'The project would perhaps have benefited from a higher intensity but shorter overall engagement process' suggests Angie Weir, one of DeNDRoN's research nurses. 'By engaging with all the groups simultaneously and using a common initial explanatory presentation, the overall timelines could have been reduced and we could perhaps have embedded the research culture more rapidly.

The challenge now comes in repeating this project in other geographical locations, in different Trusts and possibly tailoring it to different target populations.

Conclusion

From the initial audit to establish the referral pathways and the people who could be responsible for introducing the concept of participation in clinical trials, through the establishment of stakeholder groups to the increased number of patients signposted to DeNDRoN's PD-RAFT database, the project has sought to change the research culture in the neurology department at the John Radcliffe Hospital, Oxford. And, building on this success, the team is now exploring the possibility of displaying presentations and research information on wall-mounted screens within the neurosciences outpatient areas of the hospital.

PATIENTS IN RESEARCH

Tips

- Identify one hospital to undertake a stakeholder analysis of the people who act as referral conduits for patients into clinical trials and studies
- Work closely with the stakeholder groups identified through this process to pinpoint how patients access information about research
- Explore a number of communication strategies including patient targeted posters and presentations to share with these groups at focussed stakeholder meetings
- Ensure that a recognised point of contact is available in the team for each of the stakeholder groups
- Offer a simple project or study as the catalyst for engaging with the groups



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