Maximising the potential for patient participation

The Network is helping people with Multiple Sclerosis (MS) in Greater Manchester to contribute to a worldwide study aiming to find genetic factors associated with developing the disease. We spoke to Dr David Rog, Consultant Neurologist at Salford Royal NHS Foundation Trust and Dr Angela Parker, Research Delivery Manager at CRN: Greater Manchester about how they maximised the potential for patients to take part, by setting up 11 satellite sites which recruited over 2,000 patients.

“In the past there have been a number of small studies looking at genetic risk factors for the development of MS, but unfortunately those studies often only included a few hundred people, and generated potentially incorrect associations. This study, on the other hand, is a worldwide collaboration between multiple centres aiming to recruit 20,000 patients.”

Dr David Rog and Dr Angela Parker photographed at Salford Royal NHS Foundation Trust

“Maximising the potential for patient participation is therefore important for the study team to get as many samples as possible from MS patients. The team at Salford decided to widen their search, as Dr Angela Parker, Research Delivery Manager explained:

"MS patients are seen here in Salford and are also seen by Consultants across Greater Manchester. We decided that in order to maximise the recruitment to the study, we would roll out the project across a number of sites.

"We approached seven sites across the region and had a Clinical Studies Officer (CSO) in our research team to act as a main point of contact across the sites and this CSO role turned out to be key in terms of patient recruitment.

"We helped support the Trusts in terms of setting up the study and all the logistics associated with delivering a study including, taking informed consent, obtaining samples, storing samples, sending samples away for processing and recording recruitment."

Dr Rog added:

"The sample collection was relatively straightforward but the difficulty was trying to align the demands of the research with a busy MS clinic. What the Network helped us to achieve, was the logistical support to identify the patients and all the tasks that come with that, like, for example, ensuring that patients weren’t approached more than once and that the necessary paperwork was completed.

"The Network helped us to reliably capture which patients were suitable to be approached, to approach those patients, to gain their consent and to take the sample of either blood or saliva and then ensure that the sample was properly stored before it then went on to have the DNA extraction either locally or in Cambridge."

After getting the study set up and running, the team continued to assist by finding out how many patients would be at each clinic on a weekly basis and then sending the right amount of staff resource to support the clinical teams at the sites to recruit the patients and collect the samples. Working in this way was of great benefit for both the study team and the research teams across the sites, as Angela explained:

"I think the added value of the Network is that we were able to go to each of these sites across the region and establish relationships with the MSO and clinical teams. This allowed us to facilitate the set-up more easily.

"From working on this MS study we have now been able to roll out other studies across these sites more easily as we’ve already got those relationships and those working practices in place. It has also been great for the research team as it’s given them exposure to working with people with MS which will benefit the Network in the future."

"The study team’s experience of working with different sites, each with their own processes, has prepared them for working on a bigger volume of studies and studies that are more complex. As well as being an achievement for the study team, the study itself has also been a great success, as Angela explained:

"Here in Salford we have managed to recruit over 1,100 patients since the study began and including all the sites across Greater Manchester that figure is over 2,000. We really have maximised the opportunity for patients across the region to participate in a portfolio study. It’s been a great success for the patients, for the team in Cambridge and for the team here in Greater Manchester."

Dr Rog continued:

"It’s great to be part of a successful multicentre national effort. I think one of the exciting things is that this is just the beginning. There have been a number of publications already as a result of this study and one of the most exciting outputs to date is that 48 different areas in the human genome have been found that predispose to the development of MS. In other words, I can see some developments which I think will help us in the very near future."

Speaking about the Network’s contribution David added:

"We would not have been able to deliver this study let alone achieve the success we have had in recruiting over 2,000 patients without the support of the Network. That, and some innovative thinking from Research Delivery Managers Lynne Owen and Dr Angela Parker, helped us to deliver an opportunity for patients to take part in what has been some very cutting edge research."

“I consider this study to be an exemplar of how the Network and the NHS can work together for mutual benefit and for the benefit of patients.”

If you are a patient with MS that would like to find out more about taking part in research, please speak to your specialist MS nurse or your local Clinical Research Network: www.crn.nihr.ac.uk/networks

If you are a researcher that is interested in delivering your research in the NHS and getting your study on the NIHR CRN portfolio visit: www.crn.nihr.ac.uk/can-help/funders-academics

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