



Dementia Research

THE PROVIDE STUDY

This case study demonstrates the invaluable support and assistance offered by the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN). The Network assisted 9 out of 21 of the studies selected for the Dementia Themed Call.

The NHS landscape can be a difficult one to navigate for those new to research in the NHS who do not have the knowledge or experience to take their research ideas off the page and into the NHS. The PROVIDE study is one of the studies funded by the Dementia Themed Call that may have never got off the ground without the support and assistance from the Dementias and Neurodegenerative Diseases Research Network (DeNDRoN).

The PROVIDE study sets out to measure the prevalence of visual impairments in people with dementia. It also hopes to see if there is way of reducing the number of cases where visual impairments go undetected or are inappropriately managed in people with dementia, by finding out which interventions are needed to improve patient care.

This important study is a collaborative project led by Michael Bowen, Director of Research at The College of Optometrists with the help of DeNDRoN staff across the country. This is the first study the College has carried out within the NHS funding system and they welcomed the support from the Network, as Mr Bowen explains:

“This was the first time we have led a NHS based project and all the things we thought would be problematic were made easy with the help of the DeNDRoN network. Very few optometrists are actually NHS employees and so the systems and processes in place did not immediately fit with optometric practice. DeNDRoN took the time to not only thoroughly read our proposal but also to speak to us about Optometry in order to fully understand why we wanted to work in the way that we did. This allowed them to provide specific tailored advice that could really help us along the way.”



The study faced early doubt from some professionals who thought the study's recruitment aims were too ambitious. The aim was to use a sample size of 770 patients; some based in Secondary Care and some based in care homes. The study would also be carried out across approximately 30 sites in England. DeNDRoN, however soon assured the team that the study was more than feasible, as Dr Beverley Hancock, Innovation in Practice-based Research for Optometrists (iPRO) Research Adviser at the College of Optometrists explained:

"Some people were convinced it couldn't be done. We knew we needed a large sample and we had no idea how feasible it would be to recruit such a sample in the NHS! At one stage we thought we may need a full-time researcher in each region on top of research nurses across the country recruiting the patients we needed – this would have significantly increased the amount of funding the study would have required. Luckily DeNDRoN was there to advise and told us that we wouldn't need staff as they would recruit and gain consent for us. This was one of the many weights lifted by our "Fairy Godmother" at DeNDRoN."



The "Fairy Godmother" Beverley refers to is Lesley Hall, Non-Commercial Portfolio Manager at DeNDRoN. Lesley has been the key DeNDRoN contact for the College from the early stages of the study. It was Lesley, working with the DeNDRoN Local Research Network Managers, that did the necessary legwork to prove that the study would be possible. She said:

"The study team gave us the numbers and we gained feedback from the DeNDRoN Local Research Networks across the country; which was all confident that this study was possible.

"This wasn't a typical study as it is not led by an NHS organisation or by a University and the researchers were not used to working in the NHS. Therefore once the study was funded we had to take the time to explain many of the systems and processes from scratch and share the in-depth knowledge we have from years of experience in carrying out studies in the NHS. I am so pleased that they came to us and allowed us to help them. It's an important study and it would have been such a shame if it never got off the ground."

Luckily, the study more than got off the ground. The application went through smoothly, in the required time and the first patient was recruited within 30 days. Mr Bowen continues:

"Looking back now at the efficiency of DeNDRoN, I believe we could have quadrupled the sample size and still delivered in half the time. They were a pleasure to work with and their support at all points was phenomenal. As a resource, I can't image where we would be now without them."

Beverley Hancock concludes:

"I don't think people realise how good DeNDRoN is at recruitment and consent and just how vital that is in a large scale study which is widely spread geographically. We couldn't have done it without them."

The study is currently recruiting in secondary care trusts and recruitment in care homes will begin in the New Year. This will use the research ready care home network developed as part of the DeNDRoN Enabling Research in Care Homes (ENRICH) programme.

