

## **GIVING PATIENTS THE CHANCE AND THE CHOICE: DEVELOPING 3RD SECTOR PARTNERSHIPS**

### **Project Description**

**Recruitment into research projects and clinical trials can be challenging, and often relies on research-friendly healthcare professionals to drive it forward locally. One project in East Anglia decided to approach this idea from the other side, by raising awareness of research with patients directly in order to empower them to ask their healthcare team proactively about research opportunities.**

**This project entailed forging close relationships with several of the main voluntary organisations operating locally to offer their membership more constructive and tailored information about research.**

### **Introduction**

Building partnerships with key voluntary organisations working in the dementias and neurodegenerative diseases sector was key to raising awareness about opportunities that existed to get involved in research, which was the focus of this project in East Anglia.



To do this, a small, focused team embarked upon an ambitious project to establish good working relationships with three voluntary organisations relevant to its disease focus – Parkinson's UK, the Motor Neurone Disease Association and Alzheimer's Society. The main aim of this initiative was to engage with patients to allow them to participate in research.

### **Project Design and Implementation**

Although a steady increase in the number of dementias and neurodegenerative diseases research studies taking place locally has been seen in the East Anglia region, recruiting to these studies has often been a challenge. As part of this project, the local research network spent time speaking with researchers, patients and network staff to explore the reasons why patient participation into research studies and clinical trials is often so difficult. This dialogue identified that patient access to research was often restricted due to the current culture where research may not be optimally supported or promoted by healthcare teams. Often the only patients being given the opportunity to become involved were those whose clinicians were researchers. This active involvement and enthusiasm for research, however, was only present in small pockets of best practice, leaving a largely untapped resource of patients who might want to get involved but who could not.

Gloria Calderon, Senior Clinical Studies Officer in Cambridge, describes how this understanding helped to crystallise thinking about how to improve patient access to information about research. "Voluntary organisations and support groups provide a vital local service to patients and carers. We decided to try to work with these groups in a more structured way and to formalise these relationships. And, by doing this, we then had a new platform to talk to patients directly about research and to encourage patient participation in studies".

### **Impact of the Project**

The project intended to revolutionise patient participation in research from within by changing the paradigm that previously relied on asking patients to participate in research to one in which patients are given the option to request information and to ask about opportunities to participate in research.

Dr Adrian Jackson, Clinical Studies Officer in East Anglia, was delighted with the response the team

received both from the patients and from the voluntary organisations in the area. "Patients and carers are so supportive of the NHS and of research programmes running across it. And the voluntary organisations were very welcoming to the network. We were invited to local meetings to give talks and to discuss the whole spectrum of research from new treatments to new care pathways".

From a baseline of limited contact with the three main voluntary organisations in the region, the network rapidly moved to a position of having improved contact and interaction with them. This was particularly true for Parkinson's UK and the Motor Neurone Disease Association. These organisations were enthusiastic to maintain regular contact and the research network was and continues to be invited to regular local patient support and volunteer meetings.

Alan Wilcher, a carer and an active volunteer with Parkinson's UK, was delighted when they were approached after hearing a talk about research. "We have an excellent healthcare system and to realise that we could be actively helping it with research programmes was an eye-opener". He continues "With research, you have to keep your mind open or you might miss something and, for Parkinson's that is particularly true because the research can be very wide-ranging. It isn't just about interventional studies. There is so much more out there that we can get involved in and that could really help to transform day-to-day care and improve the patient's quality of life".

### Challenges and Learning Points

Patient empowerment is a tried and tested method which has been proven to work in other parts of the NHS. Examples of successful 'patient power' include the NHS 'Clean your Hands' campaign where patients are empowered to ask clinicians to wash their hands, or 48 hour GP appointments, which came to fruition as patients started to demand improved access.

However, this project was not without its challenges.

Working with the dementias and neurodegenerative diseases voluntary organisations highlighted that there was a paucity of relevant trials running in the region. This meant that time spent empowering patients to ask about relevant research studies was met by the realisation that patient enthusiasm needs to be matched with studies to promote.

With Join Dementia Research, volunteers are able to see what studies they match to and are available in their region. Registrants can also be notified of new studies being added to the service that they may be eligible to take part in.

Healthcare professionals are also able to request a Join Dementia Research account to find out what studies are recruiting locally. Please visit [nhs.joindementiaresearch.nihr.ac.uk](https://nhs.joindementiaresearch.nihr.ac.uk) for more information.

### Top Tips

- Recognise the pressures that staff face in taking on additional work above and beyond their normal duties and ensure that activity is aligned to available time, being realistic with demands
- Examine the voluntary organisations operating in the area to establish a baseline of what each offers, how regularly the groups meet, how many people attend the meetings and what studies are currently available locally that are of interest to the voluntary organisation membership
- Establish good channels of communication with key people at the local voluntary groups
- Consider connecting to local Alzheimer's Scotland and Alzheimer's Society Offices and Alzheimer's Research UK research networks

Join Dementia Research works in partnership with Alzheimer's Scotland, Alzheimer's Research UK and Alzheimer's Society. The service allows anyone to express an interest in taking part in dementia research studies without committing themselves to research. As registrants are matched to studies, they can then decide to take part on a case-by-case basis.

For more information visit:  
[nhs.joindementiaresearch.nihr.ac.uk](https://nhs.joindementiaresearch.nihr.ac.uk)