

Changing Attitudes

Working with Parkinson's UK to raise the
profile of research

Project Description

Charities and patient groups across the UK play vital roles in supporting and informing those affected by a given disease or condition. Parkinson's UK is one such organisation actively working to find a cure for Parkinson's and helping improve life for everyone affected by it. With an active system of local support groups across the Thames Valley region, the Dementias and Neurodegenerative Research Network (DeNDRoN) recognised the opportunity to create strong working relationships with Parkinson's UK. A pilot project was set up, aimed at making contact with these local support groups and at encouraging those affected by the disease to get involved in research projects in the Thames Valley region. The DeNDRoN project team fanned out across the region to give talks at the neighbourhood's support groups and to raise awareness about some of the seminal research projects happening locally. Although this posed challenges in ensuring that sufficient network resource was available to address this major undertaking, the results speak for themselves. The network identified strong champions of research in the support groups, the patients identified with the needs of the research community to recruit people into trials, and the study coordinators and leads witnessed a significant upswing in the number of patients willing to participate.



PARTNERSHIP



CASE STUDY

When it comes to raising awareness about research, it is often those affected by the disease or condition that are the most vocal group. Their desire to get involved and their ability to bang the drum for improved treatments and care creates a powerful lobby. People with Parkinson's are particularly effective at promoting this groundswell of active involvement.

Buoyed by the charity, Parkinson's UK, they have a nationwide arena for getting information at all stages of their disease and a conduit for meeting other patients and carers through the Parkinson's UK web of local support groups. In order to get their message about research out to the most relevant and eager audiences, the Dementias and Neurodegenerative Research Network (DeNDRoN) decided to launch a project aimed at working more closely with these support groups across the Thames Valley region in Berkshire, Buckinghamshire, Northamptonshire and Oxfordshire.



Project Design and Implementation

The project was designed to investigate a new approach for embedding research into Parkinson's clinical services across the Thames Valley region. Shifting away from just the more conventional clinician-led focus on trial recruitment, the DeNDRoN team created a number of opportunities to work directly with people attending Parkinson's UK patient groups. In addition to building and fostering important relationships with the patient groups, the team was keen to promote self-referral onto a 'consent for contact' database and, more specifically, to encourage involvement in two local studies.

The Parkinson's Monument Discovery (PD Discovery) study is a large project aimed at involving 2000 patients with Parkinson's. The goal of this is to identify any so-called biomarkers that might act as clues for scientists and clinicians to determine the disease progression pathway. The second study, the PD Exercise study, is a smaller study looking to recruit just 100 patients to test the effect of long-term exercise on their symptoms, fitness, health and wellbeing.

Dr Helen Collins is the local DeNDRoN network manager in the region, she said: "The project was designed to encourage our staff members to attend group meetings to give talks about the network and the studies looking to recruit locally'. Armed with a number of leaflets and other literature aimed at raising awareness, staff also took with them expression of interest forms for the Parkinson's patient register, the network's 'consent for contact' database. Additionally, a promotional video for one of the studies was effectively disseminated across the groups.

"Each project team member was assigned a region and was responsible for all or part of a particular county. This person was then in charge of ensuring that his or her groups received pertinent and on-going interaction including verbal or email communication every quarter as well as visits or talks at group meetings and research articles for local branch newsletters every six months or so".

Impact of the Project

The two main stakeholder groups – the members of the Parkinson's UK support groups and the research community – both benefited from this comprehensive engagement strategy.

Martin Tims was diagnosed with Parkinson's in 2000 and is a very active member of his local Parkinson's UK local support group. He said: "en DeNDRoN contacted us and asked to come along to one of our meetings to discuss these research projects, it seemed like too good an opportunity to miss". A passionate patient and public involvement advocate, he continues: "Being approached by your consultant or by another member of the healthcare team to participate in a research project works but finding out about local trials and being empowered to ask your doctor about possible involvement in research studies is great. Patient and public involvement strategies like this are definitely synergistic. If some recruitment comes via the consultant and some comes via self-referral, the overall effect is greater than the sum of the two'. For Martin, the relationship with DeNDRoN that has been established is vital. 'Parkinson's is what I call the ultimate designer disease in that it affects patients very differently on an individual basis whether at different times or in different ways. Therefore, having this on-going partnership is so important as it allows us to have a continuing exposure to information about research projects in the area."

Dr Johnny Collett, Research Fellow in Movement Science at Oxford Brooke's University and project lead for the PD Exercise Study, agrees. "Through this initiative to engage with local support groups, we've worked with DenDRoN and the local groups access to a lot of really engaged and research enthusiastic patients we otherwise may not have had the opportunity to talk to". The million-dollar question though is did it work? Dr Collett is certain. "We've already managed to recruit over sixty patients into this study and about a third of them first heard about the project through one of the talks at their local group."

It isn't just the recruitment figures that stack up in favour of this initiative. When the total staff costs for this project were analysed, the network discovered that the overall per patient recruitment cost was £81. This is significantly lower than the previous figure for recruitment into the PD Discovery and PD Exercise studies of around £103 per patient.

Challenges and Learning Points

Olivier Bazin, DeNDRoN's project manager who piloted this initiative, describes the tasks that the team faced in implementing it. 'The Thames Valley region covers a huge strip of central England from Northamptonshire in the north to Berkshire in the south. And, within this area, Parkinson's UK has over twenty local support groups. In order to engage with as many of these groups as possible, the first challenge was a systematic approach to identify the main contact person at each group, to find out the frequency of the meetings and the number of attendees and, of course, to explore the possibility of the DeNDRoN team being invited to present about local research projects'



Route of identification of PD Exercise study participants. This provides strong evidence of the effectiveness of engaging directly with PD groups.

There have been important learning points for the network too. Engaging with diverse patient groups can be a challenge. With many of the local support group meetings held in the evenings, there is the added difficulty of out-of-office working hours as staff travel to and from the groups and spend time preparing presentations to be given to lay audiences. However, Olivier Bazin is confident that these issues are being overcome. "The feedback that we've received has been very positive and not just from the local support group members. They have benefitted from liaising with us as it introduces them to new trials and studies that they may be able to get involved with. And, for the staff, this initiative has also presented great opportunities to engage with patients at a grassroots level. By breaking down these barriers, we have created new partnerships that are advantageous for everybody and that can only be a good thing".

Conclusion

The success of this initiative has meant that the network has forged a meaningful partnership with Parkinson's UK as an organisation both nationally and locally. The charity's website now features many of their portfolio studies and local groups have expressed a desire to continue engaging with DeNDRoN by inviting team members back to give future talks.

PATIENTS IN RESEARCH

Tips

- Collaborate with local support groups and charities by offering to visit the group to present about locally recruiting studies and to distribute relevant literature
- Build strong relationships with key contacts at each group
- Create long-term partnerships with the groups by offering research articles for local newsletters and biannual talks
- Enable staff engagement by setting aside time for them to prepare talks and attend meetings
- Ensure that staff are offered adequate training to allow for flexible, interdisciplinary working and that job descriptions accurately reflect the workload and reference to out-of-hours working



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