

Parkinson's UK Patient and Public Involvement pilot

PARKINSON'S^{UK}
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In 2015, we ran a pilot project to facilitate meaningful and high quality Patient and Public Involvement (PPI) in Parkinson's research. The role of patient organisations in supporting involvement in research has largely been unexplored – so we felt it vital to have the project independently evaluated. Here we summarise the impact of our PPI pilot on the research and the people involved.

The pilot involved:



We organised, funded and facilitated the first meeting between the researchers and PPI volunteers and supported any follow-up involvement activities after this meeting.

Findings

The overall conclusion from the evaluation is that the pilot was very successful. It helped to promote good practice in involvement and ensured that the involvement was good quality and made a positive difference to the research.

Impact of our support

Working with Parkinson's UK made involvement a simple process for the researchers. They highly valued the practical support and expert advice from the staff. This support helped to overcome some of the common barriers to involvement – not having the time, resources or know-how to find the right people to involve.

The researchers also valued working with a group of trained volunteers who had some understanding of research.

“They were able to give an informed opinion because they had a level of understanding about the research process – that is a best practice model to me.” [Researcher](#)

Impact on the research

The two main areas of impact that the involvement had on the research were **improving the written information** and **study design**.

Improving the written information

The volunteers were able to share their insights on how to make the research more appealing and understandable to people affected by Parkinson's. They commented on a range of written information, such as lay summaries, posters and questionnaires.

“It's important to make sure that the public understand what we're doing and why we're doing it – it is their money after all.”

Researcher

One of the most important lessons for the researchers was learning that their own expectations about what patients and carers would want to hear about did not actually reflect what people wanted to know.

“I learnt that participants want to feel that every tick they put on a questionnaire is valuable. So each question should be accompanied by an explanation of why this is important. This proved to be a light bulb moment for me.”

Researcher

Improving the practical design

The volunteers drew on their experience of day-to-day life with Parkinson's to provide a reality check for researchers to help make the research design more practical. This had significant implications for: the quality and quantity of data that could be collected, the experience of the participants, and conserving time and resources.

“They were able to highlight small but massively important things. These are the practicalities that need to be ironed out before you conduct any research.”

Researcher

Carers and partners also had an important impact in highlighting that their perspective could be different from someone with the condition. In one case this input resulted in the inclusion of carer interviews into the study design.

100%
OF RESEARCHERS WOULD INVOLVE PEOPLE AGAIN

Impact on the people

For some researchers this was the first time they had met anyone affected by Parkinson's and the experience had a profound effect on them both personally and professionally. It made them realise there are people behind the numbers and graphs, and emphasised the importance of ensuring that research brings clinical benefit.

“I got a completely different perspective on what the science is about. Before I didn't understand the personal stake that these patients have in the research.”

Researcher

The volunteers reported great benefits from being involved. This included gaining confidence and feelings of self-worth, and feeling more hopeful about the future. It also provided a much-valued opportunity to meet other people affected by Parkinson's.

“It gives me a sense of self-esteem. You feel valued and that you can contribute something.”

Volunteer

Read the full evaluation report by
Dr. Kristina Staley, TwoCan Associates

Next steps

As a result of the success of the pilot, we will be launching a new Research Partnership Award for Parkinson's researchers. Successful applicants will receive hands-on support and advice in developing appropriate PPI activities, including facilitation and funding of the first meeting with PPI contributors.

To find out how to apply please email researchinvolvement@parkinsons.org.uk