
Example 1: Bridging the gap between memory decline and medication in Parkinson's disease (PD)

About the research

Lead researcher: Professor Nicky Edelstyn, School of Psychology, Keele University.

Funder: National Institute for Health Research (NIHR) Research for Patient Benefit (RfPB) Programme.

Project aim: To explore the impact of medication on memory decline in Parkinson's Disease (PD).

Type of research: Clinical research.

Duration: Two years - started in April 2013.

Who we spoke to

We interviewed the lead researcher Nicky Edelstyn. Her comments are in blue below.

About the involvement

How patients influenced the research question

In a previous, small-scale study looking at the effects of timing of medication on PD, patients commented that their memory was better when they were off medication, that is first thing in the morning before taking their first dose. This anecdotal evidence was supported by the data. The research team therefore decided to investigate this effect in more detail, to understand the implications for treatment and care.

Patient / carer involvement prior to applying for funding

Nicky first talked to the Research and Development (R&D) facilitator in the local trust about seeking funding for the project.

“ The R&D facilitator opened up this big area of support which I had been unaware of and put me in touch with the Research Design Service (RDS). The RDS encouraged me to involve patients and carers in the research design and helped me obtain an RDS bursary to fund the involvement. ”
Nicky

She then met with a group of four or five patients and carers who were recruited via the Secretary of the local branch of the Parkinson's Association. They met for a pub lunch and discussed the project proposal in the afternoon. The RDS bursary covered people's travel expenses and lunch.

“ We met in a pub as the office was too formal and might have been off-putting. The local café was too noisy. We also wanted somewhere that was an equal distance from where everyone was coming from.

It worked very well. We drank soft drinks, had a meal and chatted about who we were and why we were there, what we hoped to get out of it, and what they felt about talking to us. Afterwards everyone felt more relaxed and I presented the design of the project as it was then and asked for their comments. I had a note-taker with me so I could focus on talking to them. ” Nicky

Impact of the early involvement

The patients and carers influenced the **outcome measures**. The researchers had only considered the effects of medication on memory performance. They had not previously considered the effects of memory impairment on the patients' day-to-day activities, their confidence and self-esteem. In response to the patients' and carers' comments a quality of life measure was added to the study.

The patients and carers also commented on the **practical arrangements** for participants. For example they advised that having two assessments in one week was too much and that patients needed time in between to recover (each assessment requires a period without medication). They also advised on the additional support that patients might need during the period off-medication. This led to the development of a care package for the participants.

Continuation of involvement following funding

One person who came to the first meeting said they are interested in joining the study Steering Group and continuing to work with the project. Nicky is currently discussing their potential role with them.

“ I'm going to explain what I would like them to do and find out what they would like to do so I make it clear that it's an even playing field. I've got some funding for training to build their knowledge and understanding of research. ” Nicky

Most of the group didn't want to be involved in a more formal way or commit to regular meetings. This highlights one the advantages of meeting in a pub - it enabled patients and carers to share their ideas without having to go into a research environment.

Lessons learnt

“ I would have involved patients and carers much earlier because I wasted time putting my application together before I spoke to them. Then it required all of this modification following their input. It improved the application – there was no doubt about that. Now I involve people much earlier. I’ve learnt from my mistakes.

I don’t know why I had previously overlooked involving patients. It was a sort of Road to Damascus experience. What’s the point of doing a very researcher-led study when you’ve got this wealth of experience and knowledge just sitting there, not being tapped? ” Nicky

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Project website: Under development

References:

Edelstyn, N.M.J. Shepherd, T.A., Mayes, A.R., Sherman, S.M. & Ellis, S.J. (2010). Effect of disease severity and dopaminergic medication on recollection and familiarity in patients with idiopathic nondementing Parkinson's. *Neuropsychologia* 44(6), 931-938.

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