
Practice case study

Parkinson's from inside out: emerging and unexpected benefits of a long-term partnership

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Submission date: 9 September 2021; Acceptance date: 9 December 2022; Publication date: 26 January 2023

How to cite

Sullivan, M. and Poliakoff, E. (2023) 'Parkinson's from inside out: emerging and unexpected benefits of a long-term partnership'. *Research for All*, 7 (1), 1. DOI: <https://doi.org/10.14324/RFA.07.1.01>.

Peer review

This article has been peer-reviewed through the journal's standard double-anonymous peer review, where both the reviewers and authors are anonymised during review.

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Research for All is a peer-reviewed open-access journal.

Abstract

This article is a personal reflection on a long-standing patient and public involvement (PPI) partnership between a person with Parkinson's and a cognitive neuroscience researcher. They describe how the partnership arose, was established and evolved to produce unexpected benefits to the research and more broadly. Initially, working together helped to communicate the purpose of the research to a lay audience and to make lab-based testing sessions for people with Parkinson's as comfortable as possible. They then worked together on the steering group for a research project about Parkinson's and imitation, which led to co-designing interventions using imitation and imagination of movements to improve movements, including a dance class. Further benefits were realised through co-teaching undergraduate students about Parkinson's, establishing a broader culture of PPI within the research lab and sharing their expertise of PPI more broadly. They consider key ingredients for successful collaboration, including shared curiosity, open-mindedness and trust, as well as the importance of informal discussion and space. Challenges are also considered, including authorship of research articles and anonymity. Their account demonstrates the value of the collaboration to research itself,

but also the broader (often unexpected) benefits that can emerge when a collaboration has space and time to flourish.

Keywords: involvement; collaboration; patient; Parkinson's; co-design; co-production; co-development; co-teaching; cognitive neuroscience

Key messages

- Long-term partnership between a researcher and a person with first-hand experience of a condition can influence the process and direction of research, as well as changing the culture of involvement in a research group.
- New opportunities, ideas and benefits can emerge that would be difficult to envisage or predict at the start, and that might need time and trust to evolve.
- Space for open-ended discussion is needed to allow patient and public involvement (PPI) partnerships to develop, for example, through meetings that are informal or outside the university/research setting.

Introduction

Matthew Sullivan and Ellen Poliakoff have been collaborating for over ten years. In this article, they describe and reflect on the evolution of their collaboration between a biologist with Parkinson's and a cognitive neuroscience researcher. This is primarily a case study, which grew from a joint presentation about their collaboration, but relevant literature will also be cited. They write in the third person in order to capture Matthew's and Ellen's individual voices, as well as using written comments that were invited from other key collaborators, which are included with their agreement.

Following INVOLVE (2021), patient and public involvement (PPI) is defined as 'research being carried out "with" or "by" members of the public rather than "to", "about" or "for" them. This includes ... offering advice as members of a project steering group, commenting on and developing research materials.' Within this article, the collaboration develops from involvement at one or two stages in the research to more in-depth involvement (see also Lea et al., 2020), where it is a key ingredient in the research project. Matthew and Ellen developed the cake metaphor for involvement (Figure 1) when they co-presented about their collaboration.

Figure 1. Cake metaphor for engagement and involvement in research, developed by the authors (Source: Authors, 2023; Photograph and cake by Vicki Hillyard)

Icing = Engagement
Improves dissemination and discussion of findings, but is separate and often added at the end of the research process

Filling = Some involvement
(e.g. consultation)
An important input into the research but limited to one (or two) stages



Eggs = In-depth involvement
(e.g. steering group, co-production)
Involvement is integrated into the research process and it is difficult to separate out its influence

Background and initial contact

Matthew Sullivan was working as a senior lecturer in biological sciences when he was diagnosed with the neurodegenerative condition Parkinson's. Primarily considered a movement disorder, with effects on walking and motor control, Parkinson's can involve many other symptoms, such as reduced facial expression, communication difficulties, anxiety and side effects from medication:

The first months and years into the condition, I was flailing around with my worries, assumptions and dread while trying to manage my symptoms. Within those first few years, I began to think about how I could do something for 'the cause'. I could not see myself fundraising by running a marathon, I began to wonder, well, what can I do? At this point, thinking like an academic scientist came to the rescue. From occasional visits to a local Parkinson's UK support group, I could see that there was a need for advice on how to judge the quality of scientific evidence on new discoveries in Parkinson's.

The first time Matthew used his undergraduate teaching materials with a group of people with Parkinson's was a learning experience. However, with encouragement from colleagues and Parkinson's UK, he honed a set of resources: 'An immediate benefit was that I could take these materials back into the classroom. Later, I learned that this activity came under the headings of outreach and engagement, so these efforts had legitimacy in my professional role too.'

Around this time, Matthew began to think about possibilities of getting involved in some academic research: 'I did not have any set ideas about what kind of research. The only criterion was that the location should be easily accessible.' He found Ellen, and the Body, Eyes and Movement (BEAM) lab by googling: 'In my usual way of doing-not-quite-the-done-thing, I emailed Ellen and asked if there was any way I could be useful. It was a lovely surprise to receive a response to the effect of actually, yes, there was something I could help with.'

Ellen began engaging with the wider public during her PhD, such as giving talks to local Parkinson's support groups: 'Talking to people with Parkinson's about their experiences inspired me to begin investigating the effects of watching other people move on the condition.' One attendee suggested that she ought to research the benefits of gym training in Parkinson's, something that they had experienced first-hand. This led to obtaining funding for a small-scale randomised controlled trial (Poliakoff et al., 2013):

It was exciting and challenging to take our research out of the lab and into the community. Looking back, I realise that this was my first foray into what would now be called involvement; my research was directly suggested by people with Parkinson's, drawing on their own experiences and needs.

Matthew's email arrived at a fortuitous time in 2011, just as Ellen was planning a new programme of work in Parkinson's.

Advising on research: some involvement

Ellen was beginning to investigate the effect of Parkinson's on the hand gestures that people make during speech, working with Dr Judith Holler, an expert in co-speech gestures. Matthew gave Ellen feedback on a funding application to Parkinson's UK. His comments helped her communicate her ideas and plans more clearly, particularly the lay summary, and they obtained funding for PhD student Stacey Humphries.

Matthew visited the lab to try out the testing session that was planned for the research participants (Figure 2). Ellen describes how his input helped make the testing sessions as manageable and comfortable as possible, which also improved the quality of the data collected:

We needed to make sure that people understood what we were asking them to do, and were relaxed and communicating naturally so we could record their speech and gestures with our video camera. As well as drawing on his own personal experiences, Matthew thought about how the sessions would be for others with Parkinson's, since he has met many others with the condition.

Stacey describes how Matthew advised her 'on things like providing larger buttons to press which are easier to use with their movement symptoms, as well as breaking up longer, difficult tests with shorter, easier ones and making text bigger and more readable' (see also Meinders et al., 2022). This fits with the wider literature on the importance of people with lived experience advising on the comfort of participants (Gowen et al., 2019), trialling research tools and having a role in training researchers (Lea et al., 2020).

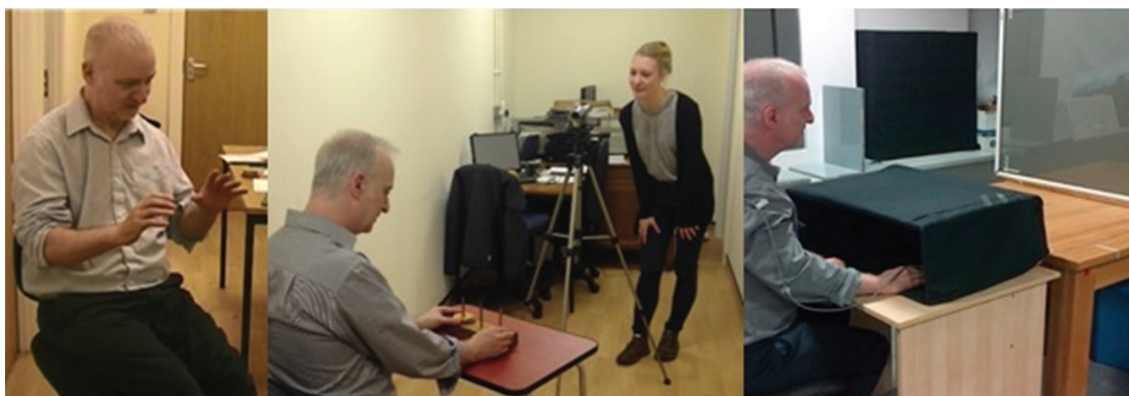
Stacey also describes the skills and insight that Matthew helped her develop: 'I learned how to communicate my research effectively to lay audiences and to the people with the greatest stake in my work, the patients themselves. By spending time talking to Matthew about his experiences, I gained insight into aspects of my research problem that I hadn't considered.'

Stacey found that people with mild-to-moderate Parkinson's made spontaneous hand gestures when talking at a similar rate to healthy older adults (Humphries et al., 2016). However, there were subtle differences when talking about actions, suggesting that people with Parkinson's may be less likely to imagine themselves doing an action. Next, Ellen explored the related topic of copying other people's actions.

Steering research: deeper involvement

In 2014, Ellen and her collaborators began an Economic and Social Research Council-funded project on the effects of imitation of movement on people with Parkinson's. Matthew's role was more firmly embedded into the entire research process – the 'eggs in the cake' (Figure 1). He commented on the grant application, and he had a key role on the project steering group, helping plans to use the project's findings to benefit society, with costs built into the grant. He attended the six-monthly steering groups, and he continued to give practical guidance on testing sessions to Dr Judith Bek (Jude), the postdoctoral researcher carrying out the project (Figure 2). Matthew comments: 'Being on the steering committee was an act of trust by Ellen, and I tried to repay that by engaging in the meetings and learning how best to contribute. I felt that my voice was listened to, and I was never patronised or ignored.' Jude describes how during meetings, 'Matthew often provided a perspective that hadn't occurred to the rest of the team, or suggested additional research questions to pursue.' Collaborator Dr Stefan Vogt describes how having Matthew in the group was 'invaluable as a source of inspiration and critical reflection'.

Figure 2. Matthew regularly visits the BEAM lab to advise on how to make testing sessions for people with Parkinson's comfortable and easy to understand, including trying out communicative, cognitive (thinking) and movement tasks (Source: Authors, 2023)



Matthew's input also helped the team to consider potential real-life implications of their findings, which showed that the movements of people with mild-to-moderate Parkinson's were still influenced by observing others' actions (Bek et al., 2018), despite their condition, and imitation could be boosted by motor imagery (imagining movements) during observation (Bek et al., 2019). Ellen observed:

The fact that there were no differences between people with Parkinson's and the healthy controls could be viewed as a 'negative finding' in the general scientific literature – if there is no difference, the experiments must not have worked. Matthew's involvement meant that we were always thinking about the possibility of using imitation to help people move, so these findings were in fact very positive.

It was also important for the team to share these positive findings with a wide audience, including people with Parkinson's, researchers and practitioners (for example, physiotherapists and dance instructors/artists).

Joint teaching about Parkinson's

Since 2014, Matthew has been contributing to Ellen's undergraduate psychology lectures on control of movement. Matthew shares his story and talks about the different types of treatment, as well as the day-to-day realities of living with the condition, for example, feeling vulnerable or people assuming he was drunk: 'Talking to undergraduates was one of the highlights of the last ten years. I think they appreciated I was frank with them, such as when I was about to undergo surgery to have deep brain stimulation fitted, and they responded equally with their questions.'

It has been documented in the PPI literature that the lived experiences of patients or service users can be successfully used to enhance training and learning for health professionals (Byrne et al., 2013). Here, the aim was to improve the students' learning about brain function, a topic many find challenging, as well as to raise awareness and reduce stigma (see Pedersen et al., 2018). Matthew's contribution was extremely well received by students; more than 95 per cent agreed that it 'added to the lecture to hear about a first person experience of a movement disorder', and many provided brief comments (see Figure 3). As Ellen reflects: 'I found it incredible to watch Matthew lecturing to our students, and their

Figure 3. Word cloud generated from open student comments about Matthew's contribution to Ellen's undergraduate lectures on the control of movement. The words 'Parkinson's', 'disease(s)' and 'lecture(s)' were removed (Source: Authors, 2023)



reactions to him. Moreover, the stories and points he shares nearly always give me new research ideas.' This led to Matthew and Ellen co-producing a video with a small group of students. Matthew was filmed being interviewed by one of the students; Ellen now uses the video in her teaching.

Co-research in translational projects

When applying the findings, Matthew's input was essential, and this was reflected in being a named co-researcher on the projects. One avenue was to use observation and imagery of everyday actions (writing, opening jars) in a home-based intervention for Parkinson's, inspired in part by Matthew's descriptions of using motor imagery, such as imagining the movement to stop himself getting stuck stirring his cup of tea. Initially, a focus group was conducted with people with Parkinson's about the idea of the intervention. Jordan Webb, a student with young-onset Parkinson's, helped facilitate the group, and he analysed the results for his undergraduate psychology project. Both he and Matthew were co-authors on the journal article (Bek et al., 2016). Matthew has subsequently been a co-applicant or collaborator on several small grants to support the development of the intervention (Bek et al., 2021). Ellen explains:

Matthew has advised on how we present the training – things like the instructions and the angle from which we film the actions. He also inspired further conversations with people with Parkinson's. Feedback on our latest film clips from groups of people with Parkinson's showed that most of them preferred the more realistic videos, including mistakes, compared to more polished and slick demonstrations.

Figure 4. Matthew and Ellen both participated in a dance taster session as part of a research-into-practice workshop, which also involved discussion of research findings and ideas (Photograph by Chris Currie)



The findings about observing and imagining actions could also be applied within dance classes. Jude obtained funding for workshops that brought together researchers, people with Parkinson's (including Matthew), practitioners and dance artists to explore this topic, and this resulted in Matthew collaborating on a review article (Bek et al., 2020). A research-into-practice project in partnership with English National Ballet followed, including the co-development of classes with dance artists, people with Parkinson's (including Matthew) and a physiotherapist (as described in Bek et al., 2022). Matthew remembers: 'We all had to overcome self-consciousness, but the professional dancers gently helped all of us with this' (Figure 4).

Unexpected benefits

The collaboration took an unexpected path, with additional elements such as co-teaching and translational work emerging over time. Moreover, there were other unexpected benefits and outcomes. First, Matthew shared technical knowledge about measuring movements using accelerometers during dance sessions, drawing on his prior scientific research on animal behaviour. Second, Matthew was introduced to other research groups and projects, where he provided advice or became a collaborator – for example, on tracking symptoms of Parkinson's (Vega et al., 2018). Third, Matthew arranged for some biology students from his university to undertake placements with Ellen in the BEAM lab. Fourth, Matthew describes the personal benefits of the collaboration:

Being able to talk about my condition in a research framework and not a sentimental way has been instrumental in forming and managing my relationship with Parkinson's. It is a degenerative disease which gets worse over time. The social interaction and mental stimulation of this PPI collaboration has certainly been good for my well-being.

Aside from influencing the trajectory of the research itself, Matthew's involvement in Ellen's research group has developed the skills and expertise of researchers, including Ellen herself (see Staley [2017] for further discussion of how involvement changes researchers). As Jude comments: 'Working with Matthew gave me a greater appreciation of the value of involving patients in research and how much we as researchers can learn from them. I have since participated in various engagement/involvement projects and events, which has enriched my work.' Matthew's ongoing input was also very motivating and grounding, reminding the team why they were doing the research. For BEAM lab, there is a culture of involvement; new researchers are expected and supported to involve people in developing their research projects. For example, when beginning a new line of research on impulse control in Parkinson's, one PhD student, Jade Pickering, used a focus group to better understand the issues, and to inform the design of her research. In parallel, the lab conducts research with autistic adults, and it is informed by consultation with experts-by-experience (Gowen et al., 2019).

Both Matthew and Ellen have received external recognition for their involvement work. Ellen's university awarded Matthew a 'Making a Difference' award for social responsibility, and his own university recognised his science communication work. More importantly, perhaps, both Matthew and Ellen have had the opportunity to share their expertise about involvement locally and nationally, serving on Parkinson's UK's Involvement Steering Group to promote involvement in research. This has included delivering training both to people with Parkinson's and to researchers, as well as developing guidelines and strategy. Their ongoing discussions about the nature of PPI have also informed their understanding and conceptualisation (for example, Figure 1), and have fed into Ellen's teaching on PPI.

Ingredients for a successful collaboration and challenges

Which elements were key to the success of the collaboration? First, both Matthew and Ellen valued involvement, and they had started involvement activities before realising that they had a name. They

share an enthusiasm for teaching and communication, as well as curiosity as scientists about 'how things work' (passion and enthusiasm are also identified as important by Liabo et al. [2020]). Moreover, as a scientist, Matthew's familiarity with the research process undoubtedly influenced the partnership, and meant that he was already comfortable with the university setting. His understanding of the challenges of obtaining funding, and the time needed to set up research, probably helped avoid some of the disappointment or misunderstandings that can arise during PPI work (for example, Lea et al., 2020). It should be noted that in other collaborations, PPI partners may have alternative relevant expertise (for example, project management, marketing); moreover, background training about the research process can be provided for PPI partners, if needed (for example, Lea et al., 2020). The importance of seeking the views of a range of people with Parkinson's, including those without a scientific background, is also considered below.

More generally, working together over time has been critical; commitment has been identified as a desirable principle of effective PPI (Baines and de Bere, 2018), and, as Lea et al. (2020: 39) describe, 'It is about relationships, and fundamentally about conversations between people.' Matthew recognises the importance of trust and communication within the collaboration:

I know that Ellen would always take my thoughts and comments seriously, gently bringing me back to reality when necessary. Ellen has managed expectations of how I am best placed to support her as time has gone on. I can be confident that I and all the PPI contributors feel in a valued partnership; that there is no them and us.

Hovén et al. (2020) also discuss the importance of trust in PPI.

Finally, both Matthew and Ellen have been open-minded about new opportunities and ways of working, allowing them to try things out, and enabling the collaboration to evolve over time. Although recommendations about PPI indicate that the role and level of commitment should be made clear from the outset (for example, Lea et al., 2020), the importance of space for development should also be considered. Indeed, meeting informally is important, for example, with lunch (see Rose et al., 2022) or outside the university – for example, at an art gallery (Bek et al., 2022). Indeed, the importance of 'informal welcoming meeting places' for PPI has been highlighted by others (Liabo et al., 2020: 2). There is a risk of losing this informality in more formal or managed PPI processes.

There are some challenges of working together. While Matthew's job gave him the flexibility to attend meetings during the day, this brought its own pressures, for example, in relation to his own work targets. Another tricky issue has been authorship on papers, and what the thresholds should be for this (see Richards et al. [2020] for discussion of this issue). For some articles, Matthew's advisory role has been reflected in the acknowledgements section (for example, Bek et al., 2019); when his input has been more central, he has been included as a co-author (Bek et al., 2016, 2020, 2021, 2022; Vega et al., 2018). There can also be practical issues, such as where revealing that Matthew is both participant and co-author could compromise confidentiality, unless carefully reported (Vega et al., 2018). Another issue has been the expectations of other research collaborators around PPI and what it entails. Sometimes, this is merely being mindful about using jargon within meetings (see Lea et al., 2020), but in other cases, researchers may be unwilling to allocate sufficient time and funding (for example, to cover refreshments, travel and vouchers for volunteers) for the process and/or change the research based on PPI. Another challenge is that over time Matthew has become quite expert in the topics being researched, meaning he may be less able to read project information from the perspective of a person with Parkinson's outside the research team. Matthew observes: 'I have become more expert in the science, but I always try to remember that I am not the psychologist, that's not my role. At times I have to curb my enthusiasm and not stray from my role.' This highlights the importance of involving others with Parkinson's, such as in the focus groups, to capture a range of views and experiences.

Concluding remarks

Matthew reflects on the changes over the last decade, and on the value of PPI: 'When we started this collaboration, I was relatively newly diagnosed. Ten years on, my condition has progressed, and so I now bring a new perspective. PPI collaborators have real lives too, which is exactly where the value of PPI lies.' This value is echoed by Ellen:

The shape of our research into Parkinson's, and the ethos of our lab over the last decade, simply would not have been the same without Matthew's involvement. In a recent talk, when I got to the acknowledgements part at the end, Matthew was actually the only collaborator who had been involved in every project in the talk!

Acknowledgements

This article developed from joint presentations at Engage 2017 and the British Science Festival 2018. We thank Stacey Humphries, Judith Bek, Emma Gowen and Stefan Vogt, and the other collaborators on the research projects, as well as the members of the Parkinson's UK Involvement Steering Group. We thank Manchester Metropolitan University and the University of Manchester for their support.

Funding

The research and involvement activities were funded by the Economic and Social Research Council (Grant Number ES/K013564/1), Parkinson's UK, a Medical Research Council Confidence in Concept award and Manchester Institute for Collaborative Research on Ageing (MICRA).

Declarations and conflicts of interest

Research ethics statement

Not applicable to this article.

Consent for publication statement

The authors declare that the informed consent of the people involved – including regarding photos, videos and any personal or identifiable information – was secured prior to publication.

Conflicts of interest statement

The authors declare no conflicts of interest with this work. All efforts to sufficiently anonymise the authors during peer review of this article have been made. The authors declare no further conflicts with this article.

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