An evaluation of a pilot project of Patient and Public Involvement in research at Parkinson's UK

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About the author of this report

This evaluation was carried out by Dr Kristina Staley from TwoCan Associates. TwoCan Associates carry out research and evaluations. They also offer training and support to help voluntary and statutory organisations involve people who use services in their work. Almost all of their work is undertaken in partnership with service users or carers.
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Introduction

1. Background

1.1   Parkinson's UK wants to fund research that is relevant and beneficial to people affected by the condition. The organisation therefore encourages researchers to work with patients and carers to design, deliver and share research. The organisation also involves people affected by Parkinson's at all stages of decision-making when funding research.

1.2   In keeping with its overall aim of supporting researchers and people affected by Parkinson's to work together on research, Parkinson's UK ran a pilot project to facilitate involvement, where they took a more active role in training and supporting all stakeholders. Prior to the pilot, the organisation had only helped researchers to find patients and carers to get involved. However, the staff were uncertain how well this was working. They wanted to find ways to ensure that the involvement was high quality and meaningful, and that researchers and volunteers felt better supported.

1.3   An invitation to take part in the pilot was sent by email to current grant-holders and co-applicants, as well as being advertised in the Parkinson's UK researcher e-newsletter. Eight research teams came forward which included a wide range of research projects and researchers. Fifty-two people affected by Parkinson's received training at five locations across the UK. The training was face-to-face and lasted a day. At the end of the training, the volunteers met with one or two researchers from one of the pilot projects. This enabled the researchers and volunteers to meet each other and ask questions. Parkinson's UK organised and funded these meetings, including paying the expenses of the volunteers. The researchers were encouraged to follow-up with the volunteers to seek further input as required.

2. Aims and methods of the evaluation

2.1   The aims of the evaluation were to find out:

- Whether this involvement had an impact on the research, the researchers and the people affected by Parkinson's who were involved.
- How this type of involvement might be best supported and delivered by Parkinson's UK.
- How to extend the pilot to future projects supported by Parkinson's UK.

2.2   The evaluation involved conducting semi-structured telephone interviews with one researcher and one volunteer from each of the pilot projects, and two staff from Parkinson's UK. Each interview lasted 40-60 minutes. With the interviewee's permission, the discussion was recorded and later transcribed. The transcripts were analysed to identify the main points for the report. Direct quotes from the interviewees are attributed to a member of staff, researcher or volunteer.

2.3   The evaluation was planned and carried out in partnership with Parkinson's UK's Involvement Steering Group, which includes two members of the Parkinson's UK Research team, four people affected by Parkinson's and two researchers. They helped to ensure the interests and concerns of all stakeholders were reflected in the overall approach.

Findings

3. The impact on the research

3.1   There were three main ways in which the volunteers' contributions made a difference to the research:

- Improving the written information about the research project.

- Improving the practical arrangements to make the research more feasible and acceptable for participants.

- Commenting on the ethical issues raised by the research.

These will be discussed in turn. The impacts are discussed in general terms in this report, while detailed case studies can be found in this document (link to case study document).

Improving the written information

3.2   The volunteers commented on a range of written information: lay summaries in grant applications, questionnaires, patient information sheets and web-based advice. Many of their comments helped to improve the language and the format to make the information easier to understand (eg encouraging the use of pictures as well as words). Often they were drawing on communication skills gained through their professional lives.

"We made helpful comments about the choice of print size and font size on how some of the questionnaires were arranged, just having it consistent and tidy, because with Parkinson's your vision can be affected as well. It was important that paperwork was laid out in a helpful way."
Volunteer

3.3   Many of the researchers thought this input was very important both for communicating with the public and potential participants.

"It's another important aspect of research these days to make sure research is communicable, that the public understand what we're doing and why we're doing it – it is their money after all!"
Researcher

"They made me realise the importance of structuring large amounts of information so that people reading it would be able to take it in at their own pace."
Researcher

3.4 One of the most important lessons some of the researchers learnt from this experience was that their assumptions about what patients and carers would want to hear about, did not reflect what people actually wanted to know.

> "We hadn't mentioned dopamine in the patient information sheet and that was what most people with Parkinson's focus on – so we had skipped over the obvious thing and gone straight into detail and that didn't make sense to people."
> **Researcher**

3.5 For example, one researcher had concerns that his study required participants to complete a large number of lengthy questionnaires. He assumed that the volunteers would help solve this problem by providing advice on the layout and formatting of the paperwork. While they did make these kinds of comments, they also explained that they would need to understand the significance and value of the questions being asked in order to feel motivated to complete the task.

> "What I learnt at the meeting is that participants want to feel that every tick they put on a questionnaire is valuable. So when you ask questions say about depression and anxiety, this should be accompanied by an explanation of why this is important. I explained how we studied every single piece of information that we collect – one volunteer said, 'That's astonishing, but that's not clear. It's just page after page of questions.' That was a penny-drop moment for me."
> **Researcher**

3.6 One researcher particularly welcomed this input as she found writing lay summaries difficult. However, she found the feedback she received confusing and wasn't certain which changes to make. She concluded that it might have worked better to have involved only one or two people in the process, and to have selected people with skills in writing in plain English.

3.7 When commenting on posters, leaflets and invitation letters for potential participants, the volunteers were able to share their insights on how to make the research more appealing to people affected by Parkinson's and how to ensure people could quickly understand what the study was about.

Improving the practical design of projects

3.8 The volunteers were able to draw on their experience of day-to-day life with Parkinson's to provide a reality check for researchers. The researchers sometimes made assumptions about what was feasible for people to do or were uncertain about what they could reasonably expect of participants. The volunteers provided advice and expertise to help make the research design more practical and acceptable for the people taking part. Such changes had significant implications for the quality and quantity of data that could be collected.

> "Certain practicalities do have an impact on the science – something as simple as: can the participant be in the MRI scanner for an hour? In terms of getting the best data from them, it comes from them being in the most comfortable position possible."
> **Researcher**

"As people with the condition, we can think of things that the researchers don't. For example, taking part in telephone interviews is difficult if your voice is affected, or whether our medication is working at that particular time of day. Most of us are much better in the mornings than we are in the afternoons. These are all the sorts of things that a researcher may not know about."
Volunteer

"Talking with the volunteers about the possible advantages and disadvantages of our new technology was an eye-opener for me. They were able to highlight small things, but massively important things. These are the practicalities that need to be ironed out before you conduct any research. "
Researcher

3.9   Similarly, some of the carers made important contributions to the research design. For example, in one study looking at people's mental health, the carers at the meeting explained that their perspective might be quite different from the person experiencing the mental health problem. On their recommendation, the researcher changed his proposal to include interviews with the carers in addition to the patients.

3.10   One of the major issues for debate with the volunteers was concerns about coming off medication. A number of the interviewees explained that this might be unacceptable for some people with Parkinson's as they would no longer be able to function and would likely experience psychological distress. In one of the studies included in this pilot, the researcher changed his protocol so that coming off medication was no longer necessary. Other projects may not have this flexibility.

3.11   The benefits of making these practical changes went further than improving the experience of the participants. One of the volunteers concluded that it would also avoid wasting time and resources as a result of going ahead with a flawed research design.

"You don't want to get the funding and then be faffing around, wasting time because patients can't talk or can't write, or something that could so easily have been addressed at the beginning, a little tweak to the methodology could have cured that before the research starts."
Volunteer

3.12   Based on one researcher's experience, being able to say you have consulted people affected by Parkinson's in developing the study, also seems to give participants confidence in the research team.

"Sometimes participants comment on what we're doing and then it's helpful to say we ran everything past people with Parkinson's disease and have made an effort to try to do this in the best way. It never suits everybody, but it's actually to reassure the participants that we have gone to that effort. It seems to give them more confidence in us as researchers."
Researcher

Commenting on ethical issues raised by the research

3.13   The volunteers were able to provide advice on ethical issues such as advising a researcher on the best time to contact people to take part. They were thus able to draw on their experience to help researchers develop an approach that would cause minimal distress to participants.

"We wanted to ask whether it would be OK to ask questions of family members or people who knew them well and whether people would be comfortable with that. Then there were issues with the genetics – we can't give participants feedback about this gene, because it's experimental and we don't know what it means for them. So we wanted to make sure people were OK with that approach."
Researcher

4. The impact of involvement on the people involved

The impact on the volunteers

4.1   The volunteer interviewees reported great benefits from being involved including gaining confidence, feeling more hopeful about the future and gaining feelings of self-worth. Many found it a very enjoyable experience.

"It gives me a sense of self-esteem… to be able to use a little bit of my experience is very important, you feel valued and that you can contribute something."
Volunteer

4.2   For some, this experience also provided a much-valued opportunity to meet other people affected by Parkinson's.

"Those of us with Parkinson's get to meet each other and there's always a huge buzz of conversation. It's not just sociable, it's like an unplanned support network."
Volunteer

4.3   A few of the interviewees seemed uncomfortable to report that they benefited personally from involvement, as volunteering is often understood to be about helping others. However, these personal benefits are extremely important to keep people motivated and engaged when there are challenges, especially when people are not being paid for their time.

The impact on the researchers

4.4   Most of the researchers involved in this pilot started with a positive attitude towards involvement and expectations that it would benefit their research. They had few prior concerns about working with people affected by Parkinson's.

4.5   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. They reported that it had completely changed their attitude and outlook.

"There's a person behind that data, where that data comes from. It was a very good experience for me to get a different perspective on what the science is about. Before, I didn't understand the personal stake that these patients have in research – which was very poignant to me once I started to talking to them."
Researcher

"There is a personal aspect not to be understated. Sometimes when there are problems with your work, it gets really frustrating, the pay isn't great, the funding's hard to come by and you think, 'What's the point?' Then you realise that the work that you're doing as researcher is very important to some people and that makes you feel good about what you're doing."
Researcher

4.6   The most surprising element for some researchers was the volunteers' level of interest in their research.

4.7   Most of the researchers took what might be described as a consultative approach to involvement, bringing prepared information sheets, protocols and questionnaires for discussion. One researcher took a more collaborative approach and looked for input into developing a new intervention. This was much more challenging for the researcher involved.

"It was quite a new experience in a way, because normally you would produce the materials first and then get people to feedback, but this time I'm involving people at a much earlier stage. It feels like you're allowing people to see that you haven't got the answers straight away. You're allowing someone to see that you're not the expert, and it's kind of a risky situation."
Researcher

4.8   All the researchers involved in the pilot had found the process extremely valuable for them and their research. All were therefore committed to involving people affected by Parkinson's in any future research projects and hope they would be able to work with Parkinson's UK again.

5. Lessons about the process

5.1   The lessons about the process are discussed in relation to the following questions:

- What types of researchers took part and at what stage in their research?

- What worked well for researchers and volunteers?

- What were the challenges for researchers, volunteers and staff?

What types of researchers took part and at what stage in their research?

5.2   Seven of the eight research projects that took part in the pilot were clinical research projects that wanted people affected by Parkinson's to participate in the research, while one was a basic science project. Researcher and volunteer interviewees were much clearer about the potential added-value of involvement in clinical research. The basic science researcher was clear that his expectations of involvement were limited to improving communication about his research:

"Parkinson's UK has been turning down grants because they didn't get through the lay panel, so that's what I really wanted, to get things as straightforward and clear as possible. The involvement made me realise that to try and find simple ways to explain the complexity of cellular life is quite a challenge and it's one I need to think about some more. I also thought that when we do produce papers they [the volunteers] could help with writing press releases and making sure that we pitch those at the appropriate level."
Researcher

5.3   Some, but not all of the volunteers were also clear about these benefits of involvement in basic science.

"At the fundamental science end there is this question of whether it [involvement] is actually appropriate. But how do you help the general public to understand fundamental science? What they need more is someone to translate complex science into plain English."
Volunteer

5.4   Although the pilot aimed to support involvement at all stages in research, in practice all the projects that came forward were looking for involvement in the design stages. Most were looking for input prior to submitting funding bids or for support with developing interventions. The researchers reported that involvement at this stage is often difficult because they may be under tight timescales to meet funders' deadlines and may have limited resources prior to obtaining funding. Therefore they very much welcomed support from Parkinson's UK at this time. From Parkinson's UK's point of view, this early involvement is more likely to generate projects that are relevant to people affected by Parkinson's and acceptable to participants.

5.5   Even at this early stage, it seemed that some researchers had already gone some way to develop an idea, which may have made it difficult for them to receive any negative feedback. They seemed to be approaching involvement as a mechanism for receiving confirmation that they were on the right lines, rather than being prepared to listen and make changes. It is very common for researchers to want to have worked up their ideas before presenting them, to avoid feeling exposed. They may therefore need more support and encouragement to work in this way.

What worked well for researchers and volunteers?

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

"It was all very straightforward. It made the session very, very easy and I didn't have any reservations or worries going into it at all. The staff really were excellent in terms of the level of communication they provided, and the level of information that they provided to the participants as well."
Researcher

"It really helped me because I didn't know where to start in terms of getting in touch with patients and carers."
Researcher

"Preparation was essential. Coming into it raw would be very awkward. The support would need to be there for anyone doing this."
Researcher

5.7   The researchers also valued working with a group of trained volunteers who had some understanding of research. They felt this enhanced the quality of their interactions with the group.

"We sensed the importance of having a lay group with some experience of research. They had a level of understanding about research design and potential biases. They gave an informed opinion, not just their own personal views, because they understood something of the research process. That is a best practice model to me."
Researcher

5.8   The volunteers very much enjoyed their interactions with the researchers. Importantly they felt their views were heard, valued and respected.

"People would listen and wouldn't criticise, and everybody was there to learn."
Volunteer

"You could tell the researchers were genuinely interested and certainly not dismissive of any changes or anything that might cause them work. I think they listened very carefully to everything that we had to say and that made us feel that we were genuinely involved in the project and we were making a difference."
Volunteer

5.9   The volunteers who received feedback about their involvement found this extremely important as it reinforced their sense of their views being taken seriously. However, there was some variation in how much feedback the researchers gave.

"You could just see the penny dropping and his face lighting up. And he summarised at the end what he'd gained from the meeting and the action points he was going to take away. That was excellent feedback. He also sent us a letter later on, thanking us for taking part and putting some of those action points down, so that was really good as well."
Volunteer

5.10   In terms of the training, the volunteers had mixed experiences depending on their expectations of involvement. For some who were totally new to research, the technical details in the training sessions were hard to absorb, although they later found it much easier to comment on the researchers' proposals. Others were reassured by the training that they did not need to understand the technical information and were there to provide their expert patient or carer views.

> "It was reassuring to realise that you didn't have to be a doctor or a technical genius to understand the research and your job was to help them put across in a succinct way what the project was trying to achieve. I feel like I then made a positive contribution. I didn't feel as if I needed any more or different training from what I had."
> **Volunteer**

What were the challenges?

5.11   The researchers who had never met with people affected by Parkinson's before had no idea what to expect and felt unprepared for managing some of the practical challenges.

> "It would have been helpful to realise there would be unique differences. One of volunteers had a difficult time speaking. His partner was there who could help translate, but it would have helped to know how to communicate with him. I think I started to speak more slowly, but then I realised that he understood me well enough."
> **Researcher**

5.12   The researchers explained that it would have been helpful to have a better understanding of what they could do to make things easier for patients and carers. They wanted to be able to accommodate the volunteers' needs at the same time as being respectful and avoiding causing offence. This goes beyond simply ensuring there is disabled access, through to having a clear picture of the specific needs of people with Parkinson's.

5.13   Despite experiencing challenges during the meeting, the volunteers seemed reluctant to express their needs at the time. This may be because they felt unwilling to speak out in the group. They thought it would be helpful if Parkinson's UK staff took the lead on making researchers aware of these issues before and during a meeting.

5.14   The volunteers identified other issues they would like researchers to be aware of ahead of a meeting, including their cognitive problems and limited facial expression.

> "Do researchers understand about things like switching off? They might think, 'She's lost the plot, what's wrong with her?' I might be looking somewhere else, I might not even be looking at them, because my peripheral vision is switched off. Or your facial expressions – somebody might be happy-go-lucky inside but they've got the mask like facial expression which might make somebody think, 'Oh they're not interested at all' – but it's quite the opposite."
> **Volunteer**

5.15   For the volunteers, the biggest challenge was the length of time involved in receiving training and meeting researchers on the same day. This was particularly difficult for people experiencing cognitive problems and fatigue. They suggested breaking up the training sessions into shorter chunks (20-30 minutes) and allowing more time for breaks. This would help them manage their fatigue and give them more time to consolidate what they've learnt.

5.16   The volunteers and the researchers suggested having more time for their meeting to ensure sufficient discussion of the projects. This suggests the training and meetings with researchers would be better held on separate days

5.17   In a few interviews, the volunteers seemed to raise stronger criticisms of the research than they had done during their session with the researcher. There may be barriers to volunteers giving what might be perceived as negative feedback in the meetings with researchers.

5.18   Parkinson's UK staff experienced some difficulties when, despite their best efforts, a few researchers did not follow through on the advice given ahead of the meetings. For example, not all researchers provided information about their project beforehand, not all prepared plain English presentations, and not all provided feedback on what they'd heard. To some extent, this is to be expected as this is a learning process for all involved and researchers may not appreciate the importance of such approaches until they have met with people affected by Parkinson's for the first time.

5.19   The staff also reported some difficulties in managing the training sessions and meetings with researchers. These included:

- Enabling everyone to make a contribution, sometimes quietening down the loud people and encouraging quieter people to speak.

- Bringing people back after going off topic in discussions.

- Closing down interesting and important discussions, when there isn't sufficient time to explore them in depth.

- Managing people's disclosure of personal problems and emotional responses in a way that's respectful and supportive.

- Managing people's misunderstanding about involvement including volunteers and researchers.

- Helping volunteers understand the project when researchers' have been unclear or overly technical in their presentations.

5.20   For example, some tensions arose through involving volunteers who had some previous research experience or technical knowledge. In these cases, the volunteer may be working with two 'different hats' and making contributions from a scientific perspective and/or from a patient or carer perspective. Not everyone was clear that the expectation was that volunteers would contribute their lay views. Others were concerned that scientific contributions from volunteers might be inappropriate and off-putting for their peers.

"One of the other volunteers went on with scientific talking – I didn't understand what they were talking about and other people were looking glazed because they were talking in jargon. It makes you feel that others are above you. How can you ever hope to understand what they talking about? It's not what we were there for."
Volunteer

5.21   Therefore the demands on the staff are very high in terms of their role in supporting and facilitating the interaction between researchers and volunteers. In effect, they are bringing together two groups of people who speak different languages, aren't always completely clear about what they are meant to be doing, may have different expectations about the outcomes and are learning together about new ways of working. Ensuring the interaction is a positive learning experience for all involved and no one loses confidence or motivation requires a considerable amount of skill in facilitation. It seems that staff have been taking on this responsibility, but without this being clear to everyone involved.

6. Expanding on the pilot project – where to go next?

6.1   This section discusses the issues that may need to be considered when rolling out the pilot to future projects. It addresses the following questions:

- What are the strengths of the approach used in the pilot?

- How could the process work as well as possible for all involved?

- Should the costs of involvement be shared?

- How might involvement be extended to other stages of research?

- How does this involvement link with other areas of involvement in Parkinson's UK?

What are the strengths of the approach used in the pilot?

6.2   All the interviewees had found the pilot project very useful. In the majority of cases, the researchers had acquired new knowledge about life with Parkinson's, their plans had been constructively challenged and they had used these insights to make changes to their research. The volunteers had enjoyed the process. They had made useful contributions, felt valued and respected. They felt they had gained personally in confidence and self-esteem as a result. In some cases where the process hadn't gone as well as hoped, everyone involved still felt the experience had been worthwhile and they had learnt a great deal.

6.3   One of the important differences between the approach developed in this pilot project and approaches used by other organisations, is that it allows for an initial face-to-face meeting between researchers and people affected by Parkinson's. The personal interaction seems to be essential for some of the valued outcomes of the Parkinson's UK process, including:

- Contributing to the development of a good working relationship between the researchers and volunteers.

- Enabling researchers to become aware of the people behind the data.

- Enabling the volunteers to understand the constraints on researchers and the research process.

- Supporting a conversation between the two parties. This enables them to learn from each other as people with different life experiences, rather than being focused on documents and the written information.

"The efficient way is to meet up and have a discussion, then they can explain it. Having a first face-to-face meeting early on is really, really important."
Volunteer

"One or two of their suggestions we wouldn't take on, because it wouldn't be scientifically sound. For example, you can't alter a standardised questionnaire. It's incumbent on us to explain those things to people – to support a two-way dialogue."
Researcher

6.4   Both researchers and volunteers discussed the importance of meeting each other outside of the clinic and separate from participation in research, as this helps to see patients as people with valuable contributions to make, rather than people with problems to fix. For this reason it is important that the language of research is not used to describe the processes for involvement. For example, it might be preferable to talk about holding meetings to consult patients and carers rather than describing them as focus groups.

"To actually talk with people with Parkinson's on a different platform is quite helpful for the researchers – to see them not on a par but in the same arena as themselves, rather than the raw data."
Researcher

How could the process work as well as possible for everyone involved?

6.5   **Matching volunteers' experience to projects**
Based on the experience of other types of involvement, the contributions that patients and carers make tend to fall into three categories[1]. Some comments relate to the kinds of issues that any lay person might make, for example commenting on the layout of a form. Some comments relate to general issues for a wide range of patients, for example mobility problems that might make travelling to an appointment difficult. Finally, there are some comments that relate to the specific experience of particular groups of patients/carers. For this reason it may become important to match people's experience to the topic being researched. For example, a project that aimed to help with communication problems in people with Parkinson's would be likely to benefit most from the involvement of Parkinson's patients with this exact experience.

6.6   In the pilot project, a mismatch in experience may have underpinned the volunteers' responses in one of the studies. The researcher was aiming to test a device to support medication management in older people. It received a poor review from the people who attended the meeting with the researcher, because these people wanted a device that would be portable, and the researcher's prototype was too big to carry. The researcher may have received a very different response from people who were less able to travel and required support with managing their medicines at home.

6.7   Similarly, a number of interviewees commented that it might be helpful to select the right volunteers to be involved in rewriting lay summaries.

"For basic science projects that have to have a lay summary, if you had somebody with a bit of expert knowledge who wanted to help the scientists, that's not the person you'd want. You'd want somebody who writes plain English, someone who knows what questions to ask and not try and understand the science, because they can advise on how to put it into better English."
Volunteer

6.8   Many projects currently funded by Parkinson's UK tend to be of a more general nature and therefore relevant to a wide range of people affected by Parkinson's. In this case, the study is likely to benefit from the input of a range of experiences – for example, including the perspectives of people who have been recently diagnosed and people who have had Parkinson's for some time. The interviewees suggested that in these cases the aim should be to include as diverse a group as possible: a mixture of ages, genders and people with different stages of Parkinson's.

6.9   **Advising researchers on ongoing activity**
Some of the researchers held additional meetings with the volunteers, some carried on email discussions with individuals and others did not have any further involvement. The intention was for researchers to lead on this ongoing activity and adapt it to the needs of the project and the interest of the volunteers. In practice, the researchers seemed to be uncertain as to how to do this. They also expressed concern about the amount of time required to maintain separate email conversations with a larger number of volunteers. This is an area where guidance from Parkinson's UK may be of value.

6.10   One of the researchers was also concerned about how to keep the volunteers engaged over the length of a project, when there might be periods of inactivity – for example, while applying for research ethics approval. They also felt unsure about how often the volunteers would be willing to be contacted for advice. On reflection they felt it would have been helpful to have a detailed conversation about expectations and the limits of involvement during the first meeting.

"It might be helpful to explain that research is unpredictable, there's likely to be lulls, there's likely to be periods of intense activity. Should I email everyone every two months in the quiet periods? Is it alright if I give them short deadlines when it's really busy and there's something to be done? You need to have that conversation up front."
Researcher

6.11   **Including people who are unable to travel**
While there were clear benefits to an initial face-to-face meeting, it will also be important to find ways to include people who are unable to travel to meetings. Their perspective is different and may be essential for certain projects. One researcher held telephone interviews with some of the volunteers who preferred to work from home and these worked very well. Home visits may be preferable – for example, when feedback is required on prototype equipment and people need to see and interact with new devices.

Should the costs of involvement be shared?

6.12   Given that the meetings between researchers and volunteers are likely to take place locally, the costs for this type of involvement should be minimal, as they only include travel expenses, refreshments and room hire (which is often free for researchers). Some of the researchers interviewed thought they would be able to cover these costs. Others reported that they had no means of paying, especially during bid development. However, if the pilot were to expand to a greater number of projects, would it be reasonable to expect Parkinson's UK to cover all the costs of this involvement?

"Funding is always tight so the more help you can get from different bodies, the better. The general cost for PPI session was very small anyway. So even the sharing of costs might be something that people might want to look into in the future. But obviously, the sweetener is that Parkinson's UK managed to pick up those costs. It makes life a little bit easier if you are trying to count the pennies within the University, as we are trying to do."
Researcher

6.13   The costs of a meeting increase considerably if it is held nationally and requires bringing together volunteers from across the UK. An important question to ask is: when are these types of meetings strictly necessary? In the pilot, one researcher requested a meeting of this kind, based on their assumption about the kind of input they needed from volunteers. As with many of the other projects, in practice the input they received was quite different to what they expected, and didn't require a geographically representative group. It may therefore be important for Parkinson's UK to evaluate researchers' requests for involvement and play a more active role in deciding which approach is best fit for purpose.

How might involvement be extended to other stages of research?

6.14   One of the aims of the pilot was to increase researchers' awareness of the value of involvement. It was hoped that a good experience at an early stage of bid development would encourage researchers to develop plans for involvement in the rest of their project. However, only a small number of the researchers asked for continued involvement in their project.

6.15   Most of the projects in the pilot asked volunteers to comment on written information about the research and the practical issues for participants. It is also possible for patients and carers to be involved at earlier stages, initially developing the research design and questions, and at later stages, being involved in data analysis, interpretation and dissemination. One or two researchers expressed an interest in these other areas of involvement, but hadn't yet developed their ideas. They were keen for Parkinson's UK to provide advice and guidance on this issue.

"The more suggestions you can get from a body like Parkinson's UK, the better really – because you have to listen to your funders, and if they're telling people how it [involvement] should be done, that can only benefit the researcher."
Researcher

6.16   There was also a suggestion that the volunteers involved at this early stage might become the people who get involved for the remainder of the project, if the researchers are successful in obtaining funding.

6.17 For Parkinson's UK there is also a question about how this involvement links to involvement in other parts of the organisation, in particular involvement in the review of grant applications. For example, there is potential for the volunteers involved at this stage to disagree with the views of lay reviewers at a later stage, which might need to be resolved. Similarly, lay reviewers may benefit from hearing the views of the volunteers who have taken part in earlier discussions.

Conclusions and recommendations

This final section includes a series of recommendations based on the findings from the evaluation and discussions with Parkinson's UK staff and members of the Involvement Steering Group.

The overall conclusion 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.

The evaluation has also identified a number of areas where there are opportunities to extend and enhance the impact of this work. These include taking steps to:

1. Promote a greater understanding of the value of involvement in different research contexts among Parkinson's UK researchers and vo lunteers.

This would:

- ensure a shared understanding across all groups of the value of involvement in basic science projects

- ensure researchers have clear expectations of how involvement will help them in their specific project

- help volunteers to have a clear understanding of the contributions they are expected to make in different research contexts

- ensure that volunteers' skills and experiences can be matched to the needs of the project.

2. Review and refine Parkinson's UK's training for volunteers, in order to:

- consider how best to meet the needs of participants who might be experiencing fatigue and cognitive problems

- support the involvement of people who are unable to travel

- emphasise the importance of contributing a patient or carer perspective, rather than the perspective of a technical expert

- encourage volunteers to be critical friends to researchers, providing constructive feedback on how research ideas could be improved.

3. Provide mentoring and support to researchers to enhance their skills in involving people.

This could include giving advice on:

- meeting the diverse practical needs of people affected by Parkinson's during meetings

- good practice in communicating with people affected by Parkinson's, including presentations

- working with people affected by Parkinson's in a respectful way, based on an understanding of how Parkinson's can affect people's interaction with others

- using appropriate and flexible methods of involvement eg teleconferences

- good practice in giving feedback to volunteers following involvement

- how to continue working with a group of volunteers after the first meeting eg being prepared to discuss and agree mutually acceptable ways of working together.

4. Increase Parkinson's UK's capacity to provide support for involvement.

Parkinson's UK staff are, in essence, providing a PPI consultancy service. In modelling good practice themselves, they provide an opportunity for others to learn how to do it. This consultancy model could benefit from further development, in particular considering:

- whether staff would benefit from additional training and support to enhance their facilitation and chairing skills

- what resources are required to meet the researchers' and volunteers' need for support, and what level of resource is available. This would help to set a realistic target for the amount of support provided across multiple projects

- whether the costs of providing this support might be shared with researchers/ other organisations.

5. Increase the extent of volunteer involvement in Parkinson's research and enhance its impact, by:

- using the levers available to Parkinson's UK to encourage all researchers to involve volunteers, including those researchers who may be skeptical of its value

- encouraging researchers to work with volunteers at an even earlier stage in the research process when ideas are first being developed

- encouraging researchers to plan for involvement at later stages in their research project, building on involvement during the funding bid development.

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List of interviewees

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