NIHR | Oxford Health Biomedical Research Centre

# Patient and Public Involvement Case Studies

## Small Grants Scheme, April 2020

This report shares case studies from the Oxford Health BRC 2019/20 PPI Small Grants Scheme. Grants were awarded for amounts up to up to £750. The funding focused on supporting patient and public involvement in the early stage of research projects or for PPI activities that were not included in an original research funding application.

The case studies describe the aim of the PPI, the activities took place, the difference PPI made and the experience of the PPI contributors.



*For more information about any of these projects or patient and public involvement at the NIHR Oxford Health Biomedical Research Centre contact: Claire Murray, Patient and Public Involvement Manager, Claire.Murray@oxfordhealth.nhs.uk*

## Patient Involvement in the Design of an Experience Sampling Methodology Study *Jessica Radley, DPhil Student, Department of Psychiatry, University of Oxford*

**What was the purpose of your PPI project?**

There were two purposes:

- To help interpret the results from a qualitative research project.
- To inform the design of an experience sampling methodology study.

**Who did you involve in your PPI activities?**

My DPhil project is looking at the needs of parents with psychosis and their families, and I asked four parents with psychosis who had taken part in my qualitative study to attend the PPI session.

**What activities were involved in your PPI project?**

We held a PPI session that included the following activities:

- Presentation of qualitative results followed by commentary by the group
- Presentation of an initial design for the next study with questions about this design posed to the group
- Creating a mindmap of what the PPI members would want to know as a potential study participant which would inform the design of participant information sheets used in the study

**How did the PPI activity impact or influence your research project?**

The PPI members in this group provided much valuable feedback. Some of the most notable elements related to the design of my experience sampling methodology were:

- Participants should all be compensated the same amount rather than providing more compensation for those who completed more daily questionnaires. Instead, participants should be incentivised by a check-up phone call with a researcher.
- Questions should be phrased positively rather than negatively to avoid distress e.g. 'Do you feel like you can trust people?' rather than 'Do you feel suspicious of people?'
- A study phone FAQ should be created for the participant to be able to troubleshoot any potential issues.

PPI Influence on the Research Protocol

| Points raised | Changes made |
|---|---|
| *How do I answer a question about my child if they're not with me?* | Surveys will only appear after school and on weekends |
| *You shouldn't incentivise people to complete more surveys with money* | Every participant will be paid a fixed fee |
| *Frame survey questions positively* | 'I feel suspicious' -> 'I feel like I can trust people' |
| *Mobile phones may be difficult to operate* | Provide a set of instructions alongside study phones |
| *Parents have different schedules depending on age of child* | Tailor daily start and end times to each participant |

**What was the experience of your PPI contributors?**

Every person reported they'd had a positive experience. Someone said they felt they were adding value to the research study and someone else mentioned that they felt like they were 'giving something back and there is some use out of my illness not just sadness'. PPI members also mentioned they enjoyed meeting and talking to other parents who had been through a similar experience to them.

**What worked well with your PPI project and why?**
I originally wanted a larger group but having only four PPI contributors as well as my supervisor and me made the group more intimate and potentially allowed members to feel more comfortable contributing.

**What would you have done differently in your PPI project and why?**
Unfortunately, many people I invited couldn't make the date. In the future, I would plan to have two separate sessions, held on different days of the week to allow for flexibility in member's availability.

**What are your future PPI plans for this research project?**
I would like to ask two of the people from this PPI group to pilot taking part in my study for 10 days and share their experiences at the end of this period.

*A poster has been produced summarising the PPI project and can be viewed on the Oxford Health Biomedical Research Centre website.*

## Learning from healthy volunteers who have recent experience of taking part in experimental medicine research studies *Susannah Murphy, Daisy Gibson, Lucy Wright & Ingrid Martin, NIHR Oxford Health BRC Experimental Medicine Theme*

**What was the purpose of your PPI project?**
This patient and public involvement (PPI) project had two key aims:

- To gain rich, qualitative feedback from healthy volunteers who have recent experience of taking part in an experimental medicine research study.
- To gain input and suggestions from previous participants regarding the design of a future planned study investigating the neurocognitive effects of ketamine in healthy volunteers.

**Who did you involve in your PPI activities?**
We invited healthy volunteers who had previously taken part in an experimental medicine study within the Oxford Health BRC Experimental Medicine theme to be part of the PPI.

**What activities were involved in your PPI project?**
For this PPI project we conducted 8 structure telephone/skype interviews. Ahead of the interview, participants were sent a short description of the future ketamine study.

PPI contributors were first asked a series of questions about their experience of previously taking part in a study. They were then asked to give feedback on the study design and practicalities of the ketamine study.

Interviews lasted between 20 and 40 minutes. Contributors were informed that the interviews would be recorded and that their responses would be used in a report, which would contain anonymised quotations. All contributors gave verbal consent for their responses to be used in this way.

**How did the PPI activity influence your research project?**
The PPI has delivered learning for the Experimental Medicine theme that will influence the design of future studies that recruit healthy volunteers. This includes how and where studies are advertised, the design of study document, the order of study tasks and the information provided to participants about study tasks.

The PPI has also influenced the design of the upcoming study including key information to be included in the Participant Information Sheet and an accompanying booklet.

**What was the experience of your PPI contributors?**
All interviewees gave positive feedback on the PPI process. They noted that taking the time to gain feedback on participants' experience of taking part in research showed a good commitment to the research.


*A report has been produced with the results of the PPI project and can be viewed on the Oxford Health Biomedical Research Centre website.*

## Patient and public involvement in forensic outcomes measures study *Howard Ryland, NIHR Doctoral Research Fellow and Honorary Consultant Forensic Psychiatrist, University of Oxford*

**What was the purpose of your PPI project?**

This PPI funding supported an additional meeting for the established Patient and Public Advisory Group (PPAG), which supports the forensic outcome measures study. The aim of this project is to develop a new outcome measure for use in forensic mental health services, which is rated by both patients and clinicians. The PPAG has been involved throughout the project. This is the first patient outcome measure to be developed jointly by both patient and clinicians in forensic services in this way. The main purpose of the PPI meeting was to ensure that the new outcome measure is truly relevant for the patients who will be using it.

**Who did you involve in your PPI activities?**

The PPAG consists of five people, including both men and women, all of whom have lived experience of secure psychiatric services. They were involved via a number of networks, including several national networks, such as the Quality Network for Forensic Mental Health Services, Forensic Faculty of the Royal College of Psychiatrists and the Adult Secure Clinical Reference Group at NHS England, as well as from local services. This ensured that they have a wide range of experience of services in general, but also of local services and of the wider national policy context.

**What activities were involved in your PPI project?**

The small grants scheme supported an additional face to face meeting of the group. This was the third meeting of the group.

The meeting began with a brief presentation to bring everyone up to speed. The group then reviewed data obtained during the project so far, commenting on the results from the recently concluded Delphi process. Two new draft outcome measures were reviewed for content, wording and presentation. We discussed and improved an interview schedule for the next stage of the study, which involved cognitive debriefing interviews with patients. Arrangements for the next stage beyond that, the quantitative pilot, were also considered and developed.

PPAG Participants were provided with a briefing pack in advance of the meeting and further feedback was sent following the meeting, with additional opportunities to comment.

**How did the PPI activity impact your research project?**

The impact on the project has been positive and profound. PPI input has guided the research at every stage, including shaping the design of the research, developing tools for use in the project, such as interview schedules, and shaping the ultimate outputs, such as the new outcome measures.

**What was the experience of your PPI contributors?**

Feedback collected from PPAG members has been very positive with group members reflecting on the experience of contributing to the research process:

- *"The group is inclusive and respectful… We start with a presentation to focus our minds on how the project is going. We then discuss the information. Lots of good ideas come out of the brainstorming."*
- *"…what is by far the best and most remarkable aspect of the PPAG meetings is the extent to which you have shown complete epistemic regard for the contribution the PPAG meeting members have offered and made to your research. This has made being involved with your work a truly authentic and meaningful experience. Thank you so much for this*."

Participants also highlighted the useful practical arrangements, such as the provision of train tickets ahead of time, the remuneration for time offered, and provision of refreshments as helping to make their involvement a positive experience. When asked how the experience could be further improved, group members suggested better directions to the venue, having a larger group to involve more people, and creating more time for discussions.

**What worked well with your PPI project?**

The PPAG has worked well, with a positive atmosphere at the meetings fostering very constructive discussions. The input of the participants has helped to significantly improve the project, by ensuring that the study incorporates patients' views.

**What would you have done differently in your PPI project?**

I would have ideally involved more PPI input at an even earlier stage when planning the project. If resources had allowed, I would like to have had more frequent and longer meetings.

**What are your future PPI plans for this research project?**

At the most recent meeting of the PPAG, we agreed that it would be good to extend the activities of the group. We therefore hope to continue meeting, so that the group can guide the next stages of the research project.

## Collaborating with patients and carers on an animation to share research findings *Erdem Pulcu, Postdoctoral Research Assistant, University of Oxford*

**What was the purpose of your PPI project?**
The main purpose of the PPI project was to create an animation summarising the results of experimental studies that we conducted in the past few years, in order that we are able to disseminate those findings to a larger audience in a lay language. We sought help from patient representatives in order to develop a script for this animation in a collaborative manner.

**Who did you involve in your PPI activities?**
Although we were expecting to have the involvement of more people, the current PPI project involved 2 patient representatives/carers. One of these individuals had contributed much more than expected and we are still working on the script together.

**What activities were involved in your PPI project?**
The current PPI project included the lead scientist giving a presentation describing the key findings of our research. This was followed by a brainstorming session with the PPI contributors to come up with a script of the animation. After the initial meeting, we keep on working on the script iteratively through email.

**How did the PPI activity influence your research project?**
We are still working on the project so it is early to assess the impact it will have on the perception of our research. Nevertheless, I foresee that this PPI will be key to creating a good quality animation that will improve the visibility of our research findings and help us to communicate relatively complex research ideas to a public audience.

**What worked well with your PPI project?**
As a scientist I found it very useful to engage with members of the PPI community which has really helped with broadening our vision when it comes to generating new research questions.

**What are your future PPI plans for this research project?**
I'm looking forward to finishing the current animation project and would like to disseminate the output as far and wide as possible. I am curious to know what the wider public will think about our research and the way we conceptualise underlying mechanisms of depressive symptoms.