

## **“Something quite special”?**

### **Understanding PPI experiences over time, and in the context of health research systems**

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#### **OVERVIEW**

This briefing presents a summary of the findings of research into experiences of public and patient involvement (PPI) in health research in England over time. It was conducted between March and December 2019, led by Joanna Reynolds and funded by Sheffield Hallam University.

#### **INTRODUCTION**

There is increasing expectation and requirement for patient and public involvement (PPI) in the design and delivery of health research in the UK and elsewhere. PPI is important for enabling lived experience of health conditions and caring roles to inform health research, and for allowing patients and the public to have a voice in shaping decisions that affect their lives. Recent research, for example by Green (2016) and Maguire and Britten (2018), has highlighted the need to evaluate the impacts of PPI on

health research (Green, 2016) and on understanding the status of PPI contributors within the research setting (Maguire & Britten, 2018). However, there is little understanding of how PPI intersects *other* areas of contributors' lives and what meaning PPI has for contributors beyond the health research context.

There is also continuing concern within the PPI field about how to ensure it is accessible and inclusive to people from all backgrounds so there is a diversity of experience contributing to health research design (Locock, Boylan et al 2017). Understanding more about the experiences of contributors within and across PPI roles is one step to identifying how different people can be better supported to get involved with PPI, and to feel motivated to continue doing it.

We conducted a small-scale qualitative study to explore in depth the experiences and views of five experienced PPI contributors, and nine people working in roles related to PPI to explore some of these issues. In this briefing we present the findings from the study in two sections:

- 1) The meaning that PPI has for contributors in relation to their lives outside health research; and
- 2) Views on how the structures and organisation of PPI in health research influences different people's experiences, and their capacity and motivation to continue pursuing PPI roles.

## METHODS

We used a qualitative study design to explore experience and views from individuals' own perspectives, and gathered data in 2019 through two methods – repeated interviews and a focus group – described below.

### **Interviews with PPI contributors**

We selected 5 experienced PPI contributors from around 30 people who expressed interest in participating, identified through existing PPI networks in England. Contributors had all been involved in at least 3 health research studies in a PPI capacity.

Participants were selected to reflect a range of age, gender and PPI experiences.

They each participated in 2 interviews, allowing them to talk in depth and in their own words about PPI and how it fits into the broader stories of their lives.

### **Focus group with PPI professionals**

We recruited 9 UK-based PPI professionals for the focus group, from existing networks, including:

- 6 PPI coordinators
- 2 academic researchers
- 1 representative of a health research funding organization.

The discussion lasted 1 hour 45 minutes, and participants were asked to talk about their experiences of supporting or coordinating PPI, interacting with contributors, and any challenges or changes experienced around PPI.

## **FINDINGS**

We present two key sets of findings that were identified through the repeat interviews and focus group: 1) the meaning of PPI in relation to other areas of contributors' lives, and 2) how health research structures lead to diverse experiences of PPI. PPI contributors' names have been anonymised.

### **HOW PPI INTERSECTS OTHER AREAS OF CONTRIBUTORS' LIVES**

#### **MULTIPLE EXPERIENCES AND IDENTITIES:**

Through the interviews, the experienced PPI contributors presented multiple identities in their lives that connect with doing PPI, some of which have changed over time. While all interview participants identified a single health condition or caring role that

prompted them to get involved in PPI initially, they all talked of numerous different life experiences that intersected their PPI journeys over time. Their motivations for PPI developed over time as a result of both these changing life experiences and involvement in PPI itself. Choices they make in taking on new PPI roles are shaped by multiple experiences including:

- changing family and social relationships,
- employment and careers,
- financial situations, and
- involvement in advocacy and activism for different health and social issues.

Experienced PPI contributor **GRACE** described multiple mental and physical health experiences that have occurred during her years of involvement in PPI, as well as changes in her professional career, which have influenced her contributions to PPI work:

“I am able to speak from quite a lot of different perspectives now”

**BHAI** talked of the caring roles he has undertaken for different family members, and which have exposed him to lots of different aspects of health and care over time. This, together with a need to supplement his low income as a carer, has shaped his decisions about which PPI roles to pursue, drawing on different areas of his “lived experience”.

Recognising the broad and changing experiences of PPI contributors is important for understanding best how to support them in PPI work, and to make the most of their expertise and contributions to health research.

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## VALUE OF PPI IN BROADER LIVES:

The different life experiences also shape what meaning PPI has in their lives. For some contributors, PPI takes on value akin to that of professional work, in terms of being ‘productive’, and through the status felt from progressing through PPI roles. The financial side of PPI work is important for some contributors, especially in the absence of other forms of income. Several contributors also talked of the value for them of their role in trying to tackle health and social care injustices, through PPI work.

**KENDRA'S** story highlighted a lack of satisfaction in her previous employment and career. She talked of getting involved in PPI as a way to progress and become more expert in a new field, giving her a type of status that she didn't experience in her previous career.

"[I have been] working my way through the ranks . . . to something quite special"

**KAT** talked of PPI offering her an opportunity to explore her general curiosity, related to her previous career in a scientific field, and to new, personal interests such as nutrition. She also described how she had become more motivated to use PPI to try to address "little injustices" in how others experience care.

This shows that the value of undertaking PPI for contributors includes, but goes beyond, the typical altruistic motivation of 'giving back'. It is important to recognise that motivations can change over time, according to contributors' personal situations and the knowledge and experience they develop through PPI work.

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### NEGATIVE IMPACTS OF PPI:

However, participants also identified some negative impacts of PPI on their broader lives. Some felt their social and / or family relationships suffered as a result of time spent doing PPI. Others suggested PPI had magnified frustrations with aspects of their lives, such as a lack of meaningful employment or a lack of support for their health condition or caring role.

These experiences indicate that better support is needed for many PPI contributors to help them balance PPI work with other demands on their time. They also show the potential for PPI work to be a mechanism to empower people to challenge the health research system to become more genuinely inclusive of patient and public experience.

For **BRENDAN**, his involvement in PPI led to increasing recognition of the inequalities of power around how decisions are made in research and health care. Following this negative realisation, he now sees his role as "challenging" the lack of understanding of and support for people with his particular condition, and pushing researchers to be more inclusive.

## HOW THE STRUCTURE OF HEALTH RESEARCH LEADS TO DIVERSE EXPERIENCES OF PPI

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### IMPACT ON RELATIONSHIPS:

The interviews and focus group revealed how people's experiences of PPI are influenced by the organisation and structure of health research in the UK. This shapes relationships between contributors and researchers, which can influence how well contributors feel their inputs are recognised and valued. For example, the typical short-term contracts of researchers in the UK can lead to frequent turnover of research staff and a lack of continuity of relationships with contributors. While some PPI contributors valued ongoing relationships with researchers, there was also talk of frustrations of poor communication, for example not hearing back at the end of a project about their inputs, and a sense of disappointment when projects finish with no further interaction.

PPI coordinators described the expectations on them to bring in 'more diverse' people to PPI roles, though often without appropriate resources to support this. This means they can feel they have less capacity to support ongoing relationships with existing contributors, and to understand their individual circumstances and motivations. This could also compromise the authenticity of involvement, potentially leading to tokenistic attempts to increase diversity of PPI perspectives.

Researchers also highlighted inconsistencies in expectations for relationships within the health system. An example was shared of an established collaboration between a research team and PPI contributor being criticised by grant application reviewers, implying their 'lay' perspective could be compromised by the ongoing relationship, unlike for established collaborations between researchers.

**Kendra:** “it can be really disappointing when a project ends and there is a cut-off point and you think what am I going to do now?”

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**PPI Coordinator:** “it’s sort of seen as a failing in me that the recruits that I have are all, you know, what a researcher sees as the usual suspects”

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**Researcher:** “we were told we couldn’t have [PPI contributor] as a co-applicant because he was too closely involved with the group and we needed somebody else. . . you would never say that to a research group about the statistician or the economist”

These expectations of PPI, embedded into the health research system, may lead to different kinds of relationships between contributors and researchers. Questioning these expectations and more resources for supporting relationships with contributors are important to ensure that people with a range of perspectives and lived experiences are involved meaningfully – and continue to be involved – in PPI work.

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#### POTENTIAL TO EXCLUDE:

The institutional structures of health research can lead to challenges and frustrations for some PPI contributors, meaning some might be unwilling to continue in the PPI field. One contributor highlighted the potential for ongoing relationships between researchers and their “pet patients” (PPI contributors) to lead to unfair practices about recruiting people for new PPI roles, leaving some excluded. Others talked of the difficulties in navigating financial systems (for example at universities) to claim PPI pay and expenses which can be time-consuming, and off-putting, particularly for those more reliant on income from PPI work.

Some contributors have found it hard to claim expenses for support for additional needs, such as a physical disability, which is required for them to attend PPI meetings. PPI coordinators also highlighted that research cultures mean some groups of people might be excluded from engaging with PPI due to the timing of meetings, usually during the working week.

**Bhai:** “Sent her a couple of emails and I said, Dear Professor, you know, I don't like to remind you but I'm still yet to be paid. . . Should it take five months to be paid a fee?”

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**PPI Coordinator:** “if you say to the researchers, well, are you willing to have your meeting on a Saturday or . . . in an evening, everybody suddenly goes very quiet”

This shows that the current structures and research cultures across much of the health research system in England may pose barriers to some people getting and / or staying involved in PPI work, which compromises the diversity of perspectives offered through PPI.

## CONCLUSIONS

Our research with experienced PPI contributors and professional PPI stakeholders from the field of health research in England has produced key insights which should inform changes to better support a wide range of people to enter and continue to be involved meaningfully in PPI work.

These insights include:

- i. PPI has meaning in people's lives beyond the health research context, and that contributors' experiences, knowledge, identities, and motivation for undertaking PPI evolved over time, in relation to their broader lives.
- ii. The structures, processes and expectations of the health research context in the UK influences relationships between PPI contributors, researchers and coordinators. This shapes how PPI inputs are valued, and contributors' capacities to undertake PPI roles.

Our research has several limitations to be noted. First, while the methods enabled in-depth exploration of people's experiences, the sample of PPI contributors and professional stakeholders was relatively small. Also, while our focus was on health research specifically, several PPI contributors and stakeholders had experience of PPI in other settings which we were not able to explore in detail. We recommend further research is undertaken with a larger sample, and to compare between sectors, and between the UK context and other countries.

Based on these insights we make the following recommendations for improving support to PPI in health research, to enable more people to contribute their perspectives meaningfully to the design and delivery of health research.

## RECOMMENDATIONS

- More resources should be allocated to support for PPI in health research, for example through the coordinator role, to enable individual needs and motivations for PPI to be understood and accommodated.
- Critical attention is needed to consider ways to address issues in the organisation of health research in the UK which pose barriers to people becoming or staying involved in PPI, especially people from low- income backgrounds, minority groups, or with additional needs.
- The evolving knowledge and experiences of PPI contributors over time should be better valued within health research. This should be reflected in support for building and maintaining long-term relationships with contributors within, and between projects.

## MORE INFORMATION

For a more detailed account of the findings from this research, please see the following paper (available open access):

Reynolds, J., & Beresford, R. (2020). "An Active, Productive Life": Narratives of, and Through, Participation in Public and Patient Involvement in Health Research. *Qualitative Health Research*, 30(14), 2265-2277. <https://doi.org/10.1177/1049732320961053>

A second paper is forthcoming, entitled: "It's not really just like gender, culture": Conceptualising and constructing 'diversity' through experiences of public and patient involvement in health research.

Please contact Joanna Reynolds, the research lead, for more information or copies of the research papers: [Joanna.reynolds@shu.ac.uk](mailto:Joanna.reynolds@shu.ac.uk)

## CITATION

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