

PROCESS AND SYSTEMS Values and value in patient and public involvement: moving beyond methods

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ABSTRACT

Patient and public involvement (PPI) in research has evolved over recent years, yet it often remains an ‘optional extra’ and, in some cases, tokenistic. Discussions are often focused on processes and methods, and are yet to make PPI the norm; we argue that the conversation needs to change to one of ‘value’: a culture of common values and principles across all types of research. Taking a reflexive, personalised approach, we reflect on how our team’s experiences as patients, healthcare professionals and academics have changed over time and shaped what we value, our involvement in research and the way we involve people in research. We illustrate, through our work together, the productive tensions we experience, our efforts to resolve these through analytic conversations and our ethic of responsibility to each other. Moving forward, embracing reflexivity and supporting relationships can help PPI to become integral to research; a value as opposed to a method.

KEYWORDS: ethic of responsibility, value, patient and public involvement, analytic conversations

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Introduction

Research is how medicine and healthcare move forward. We, the patients, are the partners of the scientists, medical professionals and other researchers who make it happen. Our role is crucial. Without us, there is no research. Without research, there is no progress. – Steve Chinn, patient contributor, Vasculitis Outcomes In relation to Care ExperienceS (VOICES) study¹

Discussions about patient and public involvement (PPI) in research often start with the National Institute for Health and Care Research (NIHR) definition of public involvement in research; that is ‘research being carried out “with” or “by” members of the public rather than “to”, “about” or “for” them ... an active partnership between patients, carers, and members of the public with researchers that influences and shapes research.’²

Several resources provide a structure and method to support PPI, including the UK Standards for Public Involvement in research, NIHR guidance for researchers on how patients and the public can be involved in research and co-producing a research project.^{2–4}

However, in practice, the focus of PPI is often on the processes and methods as opposed to the value it adds. PPI has evolved significantly over recent years, yet it often remains an ‘add on’ and, in some cases, can be tokenistic. To make meaningful PPI the norm, we argue that the conversation needs to change to one of value. We need to get better at valuing ‘value’ in PPI and creating a culture of common values and principles across all types of research. Quantitative and qualitative research may be very different but, fundamentally, the way we work together should be the same.

There are many ways to consider the ‘value’ of involving patients in research: an individual sense of feeling valued; working in a value-driven as opposed to methods-driven way (the importance of sharing power, including all perspectives, and building and maintaining relationships); and using public funding to produce impactful research that adds value and is of value to the people who need it. There is also an expectation from higher education institutes and funders to record and demonstrate the value and impact that PPI brings to the research they support.

Taking a reflexive, personalised approach we consider how our experiences as patients, healthcare professionals and academics have shaped what we value, our involvement in research and the way we involve people in research. We illustrate, through our work together in a real-life study, some of the approaches that we have taken to model the values and principles that we talk about and the lessons that we have learned. We also reflect on how we, as a team, and our PPI approach have developed over time and how, unsurprisingly, we haven’t always got it ‘right’. We consider how, as a community, we can move forward to ensure that PPI becomes an integral part of the research process; a value as opposed to a method.

Rosemary: academic rheumatologist

I recently stumbled across some old lecture notes from medical school. One page that caught my eye was ‘Value in healthcare’ with carefully highlighted sections on costs of drug treatments, outcomes, cost effectiveness and evidence-based medicine. This got me thinking about how my perspectives have evolved over the years since I wrote these notes. As a medical student, circa 1999, the focus was very much on clinical cost effectiveness and, to

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me, research was a randomised control trial. Patient involvement in research was delivery of a drug/intervention to a cohort of patients. While recognising that a patient's experience of care was important, the concept of using this to help improve care or in research did not feature in my medical training.

However, from my own subsequent experiences as a patient, and those of my family, I quickly realised that what we, as healthcare professionals, prioritised and what mattered to patients were not always the same thing. A broader concept of value and research began to evolve in my mind, with patients playing an important role in shaping improvements to healthcare.

My PhD provided an opportunity to explore this further. Initially envisaged by my supervisors as an evaluation of the clinical and cost effectiveness of mobile bone density scanning service to address geographical inequalities in access to services, I quickly discovered that almost all similar services set up in England had failed. No evaluation had taken place and it seemed important to understand *why* and, most importantly, *what lessons could be learned* as we set up our own service.

So, my research career began, somewhat unusually for a rheumatology trainee, with a mixed method PhD exploring how and why these similar services had very different outcomes across the UK. In short, place mattered; specifically, how differing perspectives of rurality among patients, staff and organisations interacted to shape the success or otherwise of a service innovation.⁵ In some cases, the services created were not what patients needed or, indeed, wanted.

I also learnt about the value of patient involvement in research, both as participants and research partners. Up to that point, I had been guilty of thinking 'but I know what patients think; I see them every day,' not appreciating the value of additional time and space to get at what really matters to people, as opposed to 'the curated picture' that we see in more formal clinician–patient interactions in healthcare settings.

I have tried to carry these principles forward in subsequent work across a range of rheumatic and musculoskeletal conditions, based on understanding people's experiences of illness, treatment and care delivery, to discover what works well, what needs to change and how care might be improved.

Lynn: public contributor

I became unwell in my mid-40s and had a 4-year diagnostic odyssey before becoming diagnosed with a rare, autoimmune rheumatic disease. I was forced to retire aged 50 years from a career that didn't define me but was a large part of who I was. I felt thrown on the scrapheap and that I had limited value to society. I discovered PPI at that time. Becoming involved gave me back a feeling of worth, and it made sense to me that involving people with a lived experience and a unique perspective would add value to research.

Since then, through a combination of privilege, hard work and effort I have become an experienced public contributor. This includes working as a patient researcher, being funded to do a co-produced qualitative research project on the experiences and impact of shielding on people living with a rheumatological disease, as I had to shield for that reason. I and another public contributor, Joyce Fox, developed the idea, hoping to bring the mainly quantitative data about shielding to life. We collaborated with a clinical academic, Dr Charlotte Sharp, who agreed to be

the principal investigator. Working in a non-hierarchical way and making shared decisions was a transformative experience for me, including understanding more about the challenges of getting a research project up and running.⁶

My understanding of value and values regarding PPI in research has evolved: I have realised that PPI isn't a method, it's a values and principles way of working based around conversations, relationships and true collaboration. My thinking has been very much influenced by becoming involved with the Co-Production Collective based at University College London and being part of the process to co-produce their values.⁷ Another influence has been Sarah Knowles' great paper, 'More than a method', which acknowledges the productive tensions inherent in involvement but calls for the time and space for discussion and change, building trusting relationships to facilitate this.⁸

Through a reflexive process, which is essential for meaningful involvement, I have realised that my most successful PPI collaborations are with people and teams that I share common values with and who are willing to spend the time developing relationships with public contributors. My involvement with Rosemary and the VOICES team is an example of this. It's not about 'group think' but rather about feeling like part of a team, having some control over the terms of your involvement, realising that everyone in the team needs care and consideration, and creating an open, honest space for discussion and challenge.

Vasculitis Outcomes In relation to Care Experiences

These journeys haven't always been easy in a research world that is fast paced and short of time. Individually and as a research team, we haven't always got things as right as we would have wished, and our perspectives continue to change and develop iteratively over time.

Herein, we share our experiences from working together on the VOICES study, which aims to provide evidence to guide reconfiguration of services to better meet the needs of people with systemic vasculitis, a group of rare autoimmune conditions.¹ The study is ongoing, but we have already co-produced several outputs with our patient-partners that are grounded in patient experience.¹

We illustrate some of the approaches we have taken, and lessons learnt, using excerpts from a conversation that we had where we explore different perspectives between our team of patients (Lynn and Mo), clinician researchers (Rosemary and Avril) and non-clinician researchers (Louise). Of course, we are not one-dimensional and each of us bring different (and often multiple) identities and experiences (eg as patient, carer, clinician or researcher) to the table. We discussed how we work together, the productive tensions we experienced, and our efforts to resolve these through **analytic conversations**. We framed our conversation by thinking about the **ethic of responsibility** we have to each other, to other patients, to our NHS colleagues and to the quality of the research. A link to the full conversation and associated blog by Louise Locock, 'Frankly speaking – conversations about PPI', can be found here: <https://hsruk.org/hsruk/viewpoints/hsr-uk-2022-innovation-inclusion-award-winners-frankly-speaking-conversations-about>.^{1,9}

Analytic conversations

So, what do we mean by analytic conversations? The concept is based on work by Louise Locock and colleagues that explored

involvement of services users in qualitative analysis of patient narratives to support healthcare quality improvement.¹⁰ Those involved felt that, while analysing transcripts was possible in small quantities, it was not always the best use of their time and experience. They suggested that a better approach could be for a researcher to meet with a group of users at the start of analysis, to map what to look out for and to sense-check findings with them.

In the VOICES project, these analytic conversations are more an ethos than a method or process, whereby we are all learning together, with ongoing conversations shaping our analysis and decisions.

With qualitative data you're really in the swamp and it can be quite difficult to get a really strong narrative because you're so stuck in the detail. And, so, I had taken a couple of excerpts, and just given them to a couple of patient partners and sat back and listened to their discussion about it ... and it really drew my attention to something that was there but I just wasn't picking up on it as much as I should have been. And that was the idea of people doing things because they need to feel safe.

I got a little bit lost and I just needed that prompt, I suppose, to suddenly think, 'Gosh. This is where we need to go. ... It's about creating the spaces to do that. And trying not to feel that it's just one more thing you have to try and do in your day. But that actually it's going to make a big difference to the impact at the end of it. – Avril, researcher, VOICES study

We have learned that we don't always have to agree and that differing perspectives are helpful, not harmful, but can sometimes feel uncomfortable. It is essential to understand and acknowledge our biases and spend time reflecting, individually and collectively, about our experiences. Critical to this is developing trusting relationships and safe spaces for that to happen.

You've got the patient, you've got the clinician, and the researcher ... we're all actually sitting in our own little boxes, with our own different perspectives. So, I think this is the first study that ... I've been involved in where it's more than just me and the clinician. – Mo, patient contributor, VOICES study

You need to create this safe space ... where the power differentials are openly acknowledged. But ... there's this common purpose and shared values and principles. And that means that there needs to be room, you need to create this room for what Sarah Knowles called ... these 'productive tensions'. And ... have this space for conversation and talk. But also the space to change, where actually it's okay to disagree. – Lynn, patient contributor, VOICES study

An ethic of responsibility

Underpinning this is **an ethic of responsibility**; a responsibility to attend to different perspectives, with relationships of responsibility between patients as participants, patients as research partners, healthcare professionals, and non-clinical and clinical researchers. Building on the work of Sarah Knowles and colleagues around the role of trusting relationships, productive tensions and two-way learning as a means of authentic co-production, implicit within these trusting relationships is mutual care and respect, and a 'ethic of responsibility'.⁸

Since the start of the VOICES project, two of our patient partners, including Steve Chinn who opened this paper, have died. We have reflected on potential differences in the way that clinician researchers, non-clinician researchers and patient-partners feel about involvement in research, in particular, the tension that clinicians can feel about involving very sick people in research. Implicit within this is a sense of not wishing to 'over-burden' people.

Right from being a medical student ... you realised the real privilege and trust and responsibility that's put in you as a doctor ... and I'm really, really conscious every day of the duty of care to my patients ... it's a constant tension and dilemma in my head about ... not to be abusing the trust that you have [placed in you by patients] and your ethic of responsibility as somebody's care provider. – Rosemary, clinician-researcher and chief investigator, VOICES study

However, this can be perceived as paternalism, and providing control over patients' terms of involvement was felt to be a much bigger issue than not asking.

This thing about over-burdening is really interesting. I hate the word 'burden' because it feels like I'm a burden and ... there's a paternalism there as well, or can be. There's an ethic here about giving people control over the terms of their involvement ... not saying to them, 'Come and get involved but I only want you to get involved in x, y and z areas.' Or, actually being really open and honest about what people can become involved in. And then they can make decisions based on that information. Because actually there's nothing worse than getting involved in research and finding out that you can't influence and impact it in the way that you would like to, or the way that you see is necessary. And to me, that's a much bigger ethical issue than the asking or not asking. – Lynn, patient contributor, VOICES study

Creating safe spaces and time to recognise our different perspectives has helped us to foster genuine partnerships and equality within the research team, as opposed to 'researchers over here, patients over there.'

I've sometimes ... really felt for Avril [researcher] and the dilemmas that she has faced in hearing our stories and converting that information into ... good data that can be used and that will be heard and seen ... by the right people. – Mo, patient contributor, VOICES study

I was particularly struck when Mo said, 'I really feel for Avril.' ... that intimation of equality of relationship and partnership and not being 'the other' ... it's not that Lynn and Mo are over there and the rest of us are over here. It is about fostering [a] genuine ... relationship, friendship, partnership. Having a laugh, feeling free to disagree. All of those things ... they're not perhaps quite the same in a clinical relationship. – Louise, researcher, VOICES study

Just as our perspectives on PPI have changed over the years, so too has the PPI described in the original grant application that has iteratively developed as our relationships have evolved; for example, our analytic conversations, originally within the qualitative work, are continuing across other quantitative parts of the project. This has led to the development of additional study outputs, such as a companion piece to the survey of vasculitis service providers that reflects patient experiences of care.

Moving forward

A values and principles way of working

PPI is essentially a values and principles way of working, which we believe should apply across all research studies and parts of the research process, from conception of ideas, study design, delivery and impact. Lynn is involved in several projects focused on basic science research including with the Medical Research Council and Coronavirus Immunology Consortium funded by UK Research and Innovation and NIHR. While the research methods used are very different to the VOICES study, we suggest that the values and principles underlying the involvement are fundamentally the same. Value also begets more value; as our ethic of responsibility and analytic conversations have developed, this has positively influenced creation of new outputs and brought about a gradual change in local research culture. A values and principles approach should be based on involving people in research because it is important, and cognisant of the diverse (and often multiple) experiences and identities that we each bring to the table. This helps to foster inclusivity and diversity, and awareness of the perspectives that are missing.

The importance of reflexivity

Reflexivity is an essential component of this values-based way of working. Healthcare professionals and researchers are encouraged to engage in ongoing reflection of their performance and professional development as part of good clinical and research practice. However, less focus is given to reflexivity, a sensitivity to the ways in which our individual experiences and biases influence our actions and those of others around us. While often considered the domain of qualitative research, reflexivity is equally applicable to all types of research and is central to PPI and co-production for all researchers and public contributors. Having the time and space to understand and acknowledge our biases and reflect individually or collectively about our experiences sometimes feels like a luxury but we need to make it the norm.

Measuring the value of patient involvement in research

Most grant applications now have a PPI section where applicants are expected to outline the role of PPI in the development of the study proposal and the impact of PPI. In this respect, being able to evaluate PPI involvement and 'quantify' its value is helpful in justifying allocation of time and other resources within research grants for PPI. However, it raises several important questions. Can you put a value on PPI? Who decides what is important to measure and how we will do that? Is measurement and evaluation done *to* public contributors or *with* them? How do we ensure that we don't just measure what is measurable as opposed to what is meaningful in PPI, and can we assign a value to relationships? And what do we value? The soft skills and time needed to build relationships between all members of a research team are often ignored, taken for granted and not valued in a research world where the currency is grant income, methodology and publishing in high-impact journals.

How funders can support a values-based way of working

Funders can help foster a values-based approach and support impactful research by recognising the time needed to build

relationships and create safe spaces to enable genuine partnerships and equality within research teams. PPI must be seen as an essential part of the research process so that research can meet the actual rather than the perceived needs of patients. If we don't understand what is important to people living with health conditions, there is a risk of 'rubbish in, rubbish out,' no matter how robust the research methods are, or how experienced the research team is. Research must add value and be valuable to the people who need it.¹¹ Research is hope to everyone living with health conditions.

Call to action

In the process of writing this opinion piece and in our conversations with colleagues, we realised that these values and principles have value beyond research. As highlighted by one reviewer, this approach can help create a culture of collaboration and partnership in the wider system to support meaningful therapeutic relationships for everyone. We hope that this will be the start of a conversation and that it will prompt thought and reflections.

The magic happens for me in research when we all come together like this and ... share these multiple perspectives, be able to do it reflexively, honestly so as much as possible everyone's needs are met ... and that is reflected in the outputs, that it feels like a shared collaboration and a shared endeavour. And that's magic ... in patient and public involvement when that happens, it's just the best feeling in the world. And you know I think that is what we are embodied with, with VOICES. – Lynn, patient contributor, VOICES study ■

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