Evolving Patient and Public Involvement in ARC-OxTV – Part 1 — N...

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Evolving Patient and Public Involvement in ARC-OxTV – Part 1

Mary Zacaroli

📅 7 May 2025

Guest post   PPI

Public contributor Mary Zacaroli shares her journey in patient and public involvement at ARC OxTV in part one of a two-part series. Follow her evolution from questioning her role to co-leading innovative health research projects, showcasing the growing impact of lived experience in academic studies.

ARC PPI Contributors at a recent meeting

When I became a PPI (Patient and Public Involvement) Champion for the ARC's Improving Health and Social Care theme in March 2020, I never thought that one day I would be devising and co-leading a research project.

In fact, it took a while to understand *why* I was there. Of course I was made very welcome by the theme lead,

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(the much-missed Professor Ray Fitzpatrick), but my role seemed undefined beyond being a "critical friend." It didn't help that Covid lockdown had just started, so I would sit looking at a computer screen of academics in their blurred homes, struggling to understand acronyms and their roles as they whisked through updates of their work.

I did ask questions and make the odd suggestion and received feedback that they were helpful, but beyond that there didn't seem to be much I could do. Although once lockdown had eased, I met up with a couple of academics from my theme just to get to know them better.

Part of the role was to have occasional meetings with other theme champions where I discovered I wasn't the only one to question why I was there, and we realised that the academics were also trying to figure it out.

We started thinking about the bigger potential of patient and public involvement, and how we could diversify so that we were more representative of outside society, as we were all white, mainly middle-aged, mainly Brits, and nearly all women.

Then fellow PPI Una Rennard was employed as the ARC's Public Involvement Officer, responsible for coordinating everything related to patient and public involvement and brought her wealth of knowledge and fantastic skills for process and detail. Building on the work of present and former PPIs and complementing the great work of the ARC admin team, she set about facilitating the development of a framework and systems to improve how PPI was done in the ARC, which, like all such things, took time to bear fruit.

Fast forward a couple of years and we are now a much more diversified group that better represents the local community, while the scope and range of what our involvement can be is being developed in several ways. This includes developing a road map called PPI Monitoring to Learn to better understand existing patient and public involvement.

Now that we have a bigger team, we are drawing up a database of our professional and personal skills . What we have found in the meetings to map our own expertise is how well our skills complement each other, what we can learn from each other and how much we have to offer the academic community as colleagues, to enable and enrich applied research from conception onwards

We are also making contact with other PPI groups nationally to find out what is going on in their spaces. At a national meeting in November 2023, for example, we were told about the **IDEAL project at Exeter University**, which is about improving the experience of dementia and enhancing active life. A group of PPIs, half of whom were living with dementia and half of whom were carers, had a huge impact on the development of that decade-long project.

It is still early days, we are probably going to hit road blocks, not least because the collaborative way in which we work may bump up against the hierarchical, siloed way in which academia can operate, as well as funding issues, but what I have seen is a committed, enthusiastic and helpful ARC Ox-TV team doing what they can to help us succeed, backed by welcoming theme leads who are also committed to change.

Meanwhile, within the community health and social care theme, PPI is now an agenda item where I update on what the PPI group is doing and a second PPI has joined the team, bringing with her a wealth of community-

based expertise and experience from the immigrant diaspora with whom she works. We will be using PPI Monitoring to Learn to benchmark what PPI involvement there is and what form it takes in our theme. I think one of things that we as PPIs offer though is just to reflect back to academics that they have and can access their own lived experience, their personal selves.

Relationship building within the theme also started to bear fruit in ways I hadn't imagined when Dr Caroline Potter, the staff PPI theme champion, helped me do a small piece of research for the upcycling social enterprise I used to run, to find out whether it helped improve quality of life for the vulnerable people I was working with. This led eventually to our pilot project, which is the subject of Part 2 of this blog.

What to read next

COVID-19 lockdown: Mary Zacaroli

📅 23 July 2020

We asked PPI contributor Mary Zacaroli to let us know how the COVID-19 lockdown had affected her and the third sector and PPI work she does in her own words.

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The Future of Public Involvement

📅 28 June 2021

[Opinion] [PPI]

Dr Claire Schwartz, ARC OxTV Programme and PPI Manager, shares her thoughts on the future of patient and public involvement.

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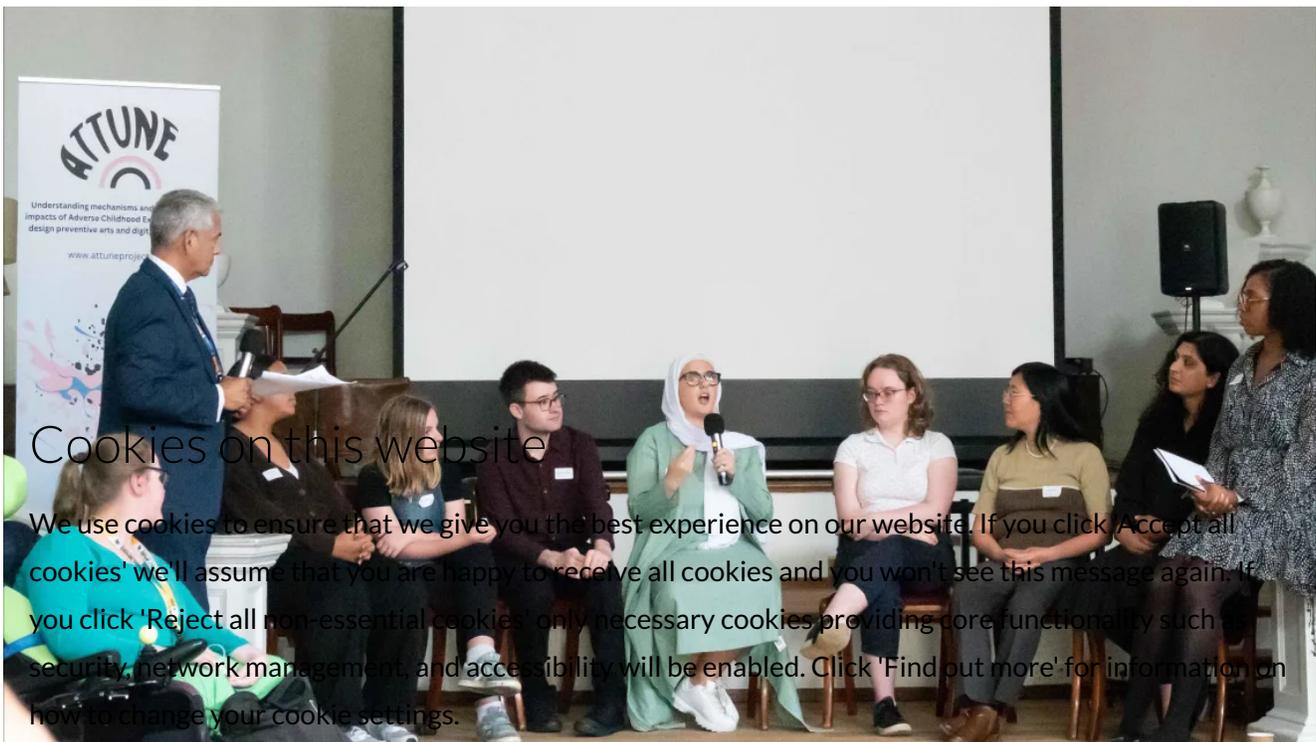
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Rose Hill Community Centre Research Showcase

A Rose Hill community research showcase brought together researchers and residents to rebuild primary care research in East Oxford. Discover how patient partnerships and meaningful engagement addressed research equity in deprived areas in this Blog by GP Dr Sharon Dixon.

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ATTUNE project: exploring childhood adversity through arts, data, and co-design with young people

The ATTUNE Project transforms our understanding of Adverse Childhood Experiences by putting young

people at the centre of research and solution design. Through creative arts workshops, big data analysis, and co-design approaches, the project developed innovative interventions including a validation-focused public health resource and a digital game for mental health awareness. Findings challenge traditional ACEs definitions and demonstrate how youth-led co-design can create more effective, acceptable mental health support tools.

Evolving Patient and Public Involvement in ARC-OxTV – Part 2

In part two of her series, Mary Zacaroli explores being an 'Expert by Experience' at ARC OxTV. Discover how she co-led an innovative pilot study using Moodscope cards to measure wellbeing in community projects, demonstrating the value of public contributors in health research.

Reflections on the OxTV ARC Showcase from the ATTUNE team

ATTUNE project researchers reflect on the NIHR ARC OxTV Showcase, sharing insights on youth engagement and lived experience research. Key discussions include NHS innovation strategies and improving children's mental health services across the region.

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Shaping health at every stage: insights from the ARC OxTV showcase

In this post Aida Checa – Events, Marketing and Engagement Manager for the NIHR Oxford Biomedical Research Centre – shares her thoughts and experiences of attending the ARC OxTV's recent Showcase event.

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