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



Mary Zacaroli

📅 7 May 2025

Guest post

Public engagement

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.

In the last blog I wrote about how things have changed in the Arc Ox-TV since I became a Patient and Public Involvement (PPI) Champion.

You may be wondering what a PPI even is? Why we would get involved in research and what we bring to the table?

We are sometimes called Public Partners, but I recently heard a term that I think explains much better who we are and what we do; that we are Experts by Experience.

That's certainly true for me: I had gained a lot of experience and skills that I had already used elsewhere, for example, when policy was being made nationally and in Oxfordshire around suicide prevention; and I see it in my fellow PPI champions.

But conceiving and co-leading on a pilot project, whereby you see if the idea is feasible, and then getting funding for it was not something I envisaged - although it has happened elsewhere, for example, the

Dementia Enquirers programme has supported over 20 groups of people living with dementia to **conduct their own small-scale research projects**.

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I had told Caroline about Moodscope cards that I had trialled before and after an upcycling class, to see if

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they showed an improvement in mood, which they did.

So, Caroline suggested we seek funding to run a formal pilot study, looking at the impact of a community-based project on health and wellbeing, using mood as a benchmark. We thought that using the cards would chime with one of the aims of the ARC, to find innovative methods of data collection.



Moodscope cards are based on the American Psychological Association's Positive and Negative Affect Schedule (PANAS scale). The cards measure 10 positive emotions and 10 negative emotions from 0 to 3, added up and then scored to form a percentage between 0 and 100%.

Moodscope was developed by a lay person, Jon Cousins, who was looking for a way to measure and track his mood each day and the positive results led him to get the cards validated and set up as an online tool.

I had used it online when going through a particularly difficult time many years before and had always liked the balanced focus of positive and negative (because of my life experiences I feel very deeply that if you just focus on what's wrong with a person, it skews your perceptions of them and their perceptions of themselves).

Having got to know the current Moodscope owners a little from writing anonymised blogs for them, they had sent me some of their demonstration cards. When I trialled them in the upcycling classes, what I also found was that they were a conduit to conversation, but that this could trigger deep-seated emotions and memories, so it was very important to have safeguarding measures in place should difficult topics come up.

All of this prior experience informed how we set up the project, while Caroline brought her many academic skills honed as an academic researcher in anthropology and primary care. She knows how funding bids work, what you need to do for applications, including how to get ethics approval, what questions to ask, how to analyse the data and the language of academic report writing as well as the knowledge of where to go to cite sources.

I brought my own research skills too, but technology has advanced hugely since 1998 when I completed my Masters, so having Caroline's help to get up to speed on the programme we used was invaluable, and all in all we made a good team.

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Together, we worked with a charity I had got to know in my upcycling days, Children Heard and Seen, that

looks after children with a parent in prison and their families. That prior relationship was a major reason why we use cookies to ensure that we give you the best experience on our website. If you click 'Accept all cookies' we'll assume that you are happy to receive all cookies and you won't see this message again. If you click 'Reject all non-essential cookies' only necessary cookies providing core functionality such as security, network management, and accessibility will be enabled. Click 'Find out more' for information on our project used the Moodscope cards to measure an arts therapy course run with two mothers and two grandmothers.

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was clear from interviewing the participants and the support workers afterwards how and why they found the arts therapy course of benefit, the impact of outside life on their scores and how doing the cards with their balanced approach to mood gave them a better understanding of the nuance of their mood; that they could be feeling really negative, but still feel positive in some ways.

More information about the course is in the video above.

What we would like to do now is a much bigger project with different groups to see how and where using these cards might be of benefit; not just about how to use Moodscope as a benchmarking project, but also how it could be used online as a research tool.

We are seeking potential collaborators from third-sector organisations and more researchers to develop this next phase, as well as funding, so if you are interested in getting to know more, please contact us via moodscopeproject@gmail.com.

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COVID-19 lockdown: Mary Zacaroli

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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.

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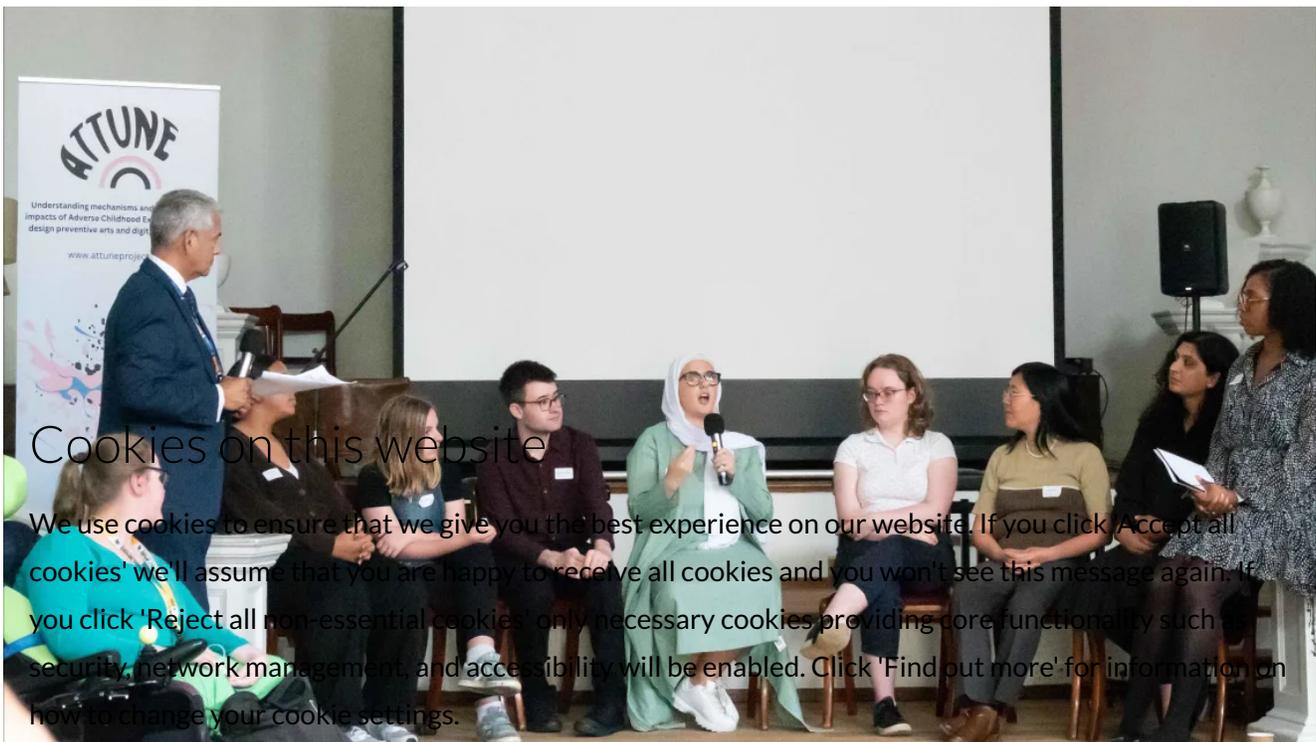
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Rose Hill Community Centre Research Showcase

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.



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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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