

Bridging lived experience and research: a public advisor's journey forward

By Jason Grant-Rowles, ARC KSS Board Public Advisor



Jason brings a powerful blend of lived experience and professional insight to his role as an ARC KSS Board Public Advisor.

Motivated by a personal journey through the mental health system, Jason has spent the past decade contributing to service improvement through research involvement, peer support, and policy influence.

His career has spanned roles from broadcast journalism to peer coaching, and he is now pursuing a PhD at King's College London focused on improving informed consent in schizophrenia research. Jason's voice continues to shape mental health research and practice, grounded in empathy, resilience, and a commitment to meaningful change.

What got you interested in public involvement or health research?

After my own positive experience of the mental health system, I wanted to help improve outcomes for others. I was asked to give feedback on a clinical trial and the researcher seemed to pay attention to my suggestions. They even came back to me, at a later date, with information about how my feedback had improved the design of the study. From that point on, I was open to opportunities to help the system make improvements for others.

Can you tell us a bit about your background?

I was born and raised in London. My family came to the UK as part of the Windrush generation in the 50's from a small island called St Lucia. Before experiencing the mental health system myself, I worked as a freelance broadcast journalist and group facilitator in prisons. I reported from across Europe and my facilitation work took me across the country.

Were there any key moments or people who encouraged you to get involved?

I was very fortunate to have had a wonderful care coordinator who challenged my thinking, got me to question things, and suggested ways to get involved in projects. I met the people participation team at the Trust who helped me to feel welcome and connected me to different groups. I also met the research involvement team who encouraged me to give advice to local researchers and join specific research interest groups.

Did you face any challenges getting into this kind of work?

The main challenge was staying on top of my own mental health challenges and trying to make sense of what had happened to me. Most people that I met who worked for the Trust were very open for me to join activities and to be included in spaces. I suppose the main difficulty was knowing that it was okay to say no to things so that I didn't stretch myself too thin. I also had to navigate a way to meaningfully use my experience to create a pathway towards being a productive member of society.

What have you enjoyed most about being a board advisor?

I have thoroughly enjoyed having a seat at a decision and influencing table of a regional research organisation that seeks to connect the research activity to the practical realities of the system. Having access to senior leaders from across the system has helped me to learn how to be more impactful with my words and actions. I am lucky to work alongside two other exceptional board public advisors and to be supported by the wider public involvement network.

Have there been any surprises along the way?

The main surprise that I have noticed is the pace of change within the system and the turnover of senior leaders. Fortunately, ARC KSS has managed to hold steady within the winds of change, which does make me wonder how much better the system would work if there was stability across the board.

How do you feel your voice has made a difference?

It is very hard to directly comment on how my voice has made a difference. I know that collectively as board public advisors our thoughts and suggestions are always encouraged. Researchers do reach out for advice and insight with their projects. During our board meetings, when I do speak, it feels like colleagues are really listening. The minutes are always an accurate reflection of the discussions, which helps to create a record of our involvement.

In what ways has your journey from lived experience through involvement in research led to the work you are doing today?

It has taken me ten years, from when I was in hospital, to get to where I am now. I started out as an expert by experience for the Trust, attending meetings, focus groups, conducting quality safety reviews, and sitting on interview panels.

Once my confidence developed, I applied for a role as a Mental Health Community Partner for the Department for Work and Pensions, covering 14 job centres in South London. I trained over 500 colleagues in the social model of disability and how to support people with mental health conditions. Once that contract finished, I applied for a Research Associate position at the University of Manchester, working on a study that explored the ethnic inequalities with severe mental distress. I worked on that study up until the pandemic and then had to contend with the lockdowns. Fortunately, I had built up a strong network and was able to access support groups online. I learned that the early intervention service that I used was recruiting a new peer support worker for the first time and I was encouraged to apply for the role.

I worked in Worthing for two years and then got a job in Islington, where I worked for three years as a peer coach, senior peer coach, and trauma informed collaborative lived experience practitioner.

Tell us about your current PhD work?

I am now embarking on PhD research project at King's College London exploring how to improve the informed consent process within schizophrenia research.

I am currently in the middle of a systematic review searching databases for articles relating to my research question. I will then screen those articles to see whether it is worth reading the full text. After reading the full text, I will then extract the information that will be used in my article. The idea is to see what has been done to improve informed consent and to see what I can do that's different.

Before my PhD, I completed a NIHR ARC North Thames Career Development Fellowship at University College London, where my work allowed me to take one day a week to develop my capacity to apply for PhD programmes.

What would you say to someone thinking about applying for a similar role?

Well, I would hope that people would not have to come into the mental health system in the first place. That being said, if one has firsthand, personal experience of illness and recovery, then I would recommend getting involved in any way that feels comfortable to join meetings and groups across the Trust. Once you have built up a level of confidence and have a better understanding of how you would like to make an impact, I would recommend seeking some shadowing experience, accessing a mentor or buddy, and applying for involvement positions.