

Event Reflection: *Suno Saheli – South Asian Voices in Research*

Date: 31st July 2025

Location: BRIG Café Birmingham

Hosted by: Cysters

On 31st July, Cysters welcomed a vibrant group of South Asian women to our *Suno Saheli – Sip and Paint* session, held as part of South Asian Heritage Month. Suno Saheli means listen friend in Punjabi. This evening combined creativity with honest conversations about involvement in health research and Patient and Public Involvement and Engagement (PPIE). Through painting the most beautiful champagne glasses or mason jar and sitting in sangat (community in Punjabi) sharing traditional desi food, we created a relaxed space to explore community experiences and aspirations around research participation.

What Does “Research” Mean to You?

We began by asking attendees what comes to mind when they hear the word *research*. Answers reflected a wide range of associations, from humorous to reflective:

- “Academics — nutty professors”
- “Collecting information”
- “Finding info to analyse”

These responses highlight the mix of curiosity, distance, and sometimes skepticism many feel towards research, highlighting the importance of making research more relatable and inclusive.

Have You Ever Been Invited to Share Your Experiences in Research or PPIE?

Most participants shared that they had not previously been invited to contribute their voices:

- “No, because maybe there’s not enough research geared towards women like me”
- “No — language problems”
- Some had engaged, but only through open calls by Cysters

This reinforced the existing gap in inclusive, accessible research opportunities for South Asian women and emphasized the unique role Cysters plays in bridging this divide.

What Would Make You Feel Safe, Respected, and Valued Enough to Get Involved?

Participants were clear about what would encourage their involvement:

- “To be paid for my time”
- “Delivered in a safe and culturally appropriate way”
- “Accommodating access needs”
- “If researchers looked like me”
- “Translation support”

These insights are vital reminders that meaningful PPIE must address both practical and cultural barriers to truly honour lived experience and this looks different to everyone in the room.

Do You Feel Lived Experience is Taken Seriously in Research? Why or Why Not?

There was a strong theme of distrust and invisibility:

- “There is a running theme of institutions disregarding women of colour and their experiences”
- “Not sure our voices are important in the system”
- “Not sure it would be valued given the hospital context of not being heard”

This feedback highlights ongoing systemic challenges and shows there is an urgent need to decolonize and diversify health research practices, if we are serious about involving communities.

What Are the Barriers to Participating in Research?

Concerns raised included:

- “Not knowing the biases the researcher could have”
- “If it was performative research”
- “Atmosphere and vibe of the place it’s being done”

These reflections confirm that building trust requires transparency, genuine intention, and culturally safe environments. It also recognises the political / global climate some of our communities are navigating in relation to the genocide in Palestine.

Why These Voices Matter — And Why Organisations Like Cysters Are Essential

Patient and Public Involvement and Engagement (PPIE) in health research is only as effective as the diversity and authenticity of voices included. South Asian women, especially those from marginalized and intersectional identities, have historically been ignored or sidelined in research, resulting in gaps in knowledge, poor healthcare outcomes, and policies that don’t meet their real needs.

This session made it clear that without trusted, culturally competent organizations like Cysters, many individuals would remain excluded from research conversations. Cysters acts as a bridge, not only connecting communities with researchers but providing the wraparound support needed to make participation safe, accessible, and meaningful.

Embedding organizations like Cysters deeply into the research process helps:

- Ensure outreach reaches those who are most underserved
- Provide cultural and linguistic support that academic institutions often lack
- Offer trusted ongoing support and advocacy before, during, and after research engagement
- Help build reciprocal relationships where lived experience is truly respected and valued

This kind of embedded partnership is crucial to dismantling systemic barriers and transforming research from an extractive exercise into a tool for real community empowerment and health equity.

Final Thoughts

Suno Saheli was more than a crafting evening, it was a powerful act of community-led knowledge sharing and a step towards shifting how research engages South Asian women. The voices heard clearly call for research that respects cultural identity, provides tangible support (like payment and translation), and builds trust through representation and safety.

We are deeply grateful to everyone who attended and shared so openly. Their insights will directly inform how Cysters continues to develop inclusive PPIE projects and advocate for systemic change in research practices.

Thank you to the University of Warwick for sponsoring this vital work, and to all those committed to making research a space where every voice matters.