

Co-production in HIV prevention research: testing equitable collaboration between academic and community leadership in the PrEP-position study

Sophia

THPED364

S. Strachan^{1,2}, C. Corrales Camargo^{1,2}, V. Rajabzadeh², M. Devonald², A. Namiba³, A. Awan¹, T.Chana⁴, K. Delatango⁵, V. Mandaza², P. Menzies-Banton⁴, Z. Nwaosu⁴, J.Otti^{1,6}, K. Ring², T. Asimi⁴, M. Smuk², N. Halim², S. Paparini², C. Orkin²

1. Sophia Forum, UK, 2. SHARE Collaborative, Queen Mary University of London, London, UK, 3. 4M Network of Mentor Mothers, London, UK, 4. The PrEP-Position Steering Group, 5. Bare Radicals, 6. Africa Advocacy Foundation

Study with underserved communities The study looked at PrEP knowledge, use, and delivery preferences among underserved communities in the UK, using surveys and interviews to better understand barriers like digital exclusion, distrust, and language that felt too clinical or intrusive.

Co-production model The project used a shared leadership model with academic researchers, a community lead, and an external evaluator, plus a steering group made up of people from minoritised communities, so community voices helped shape the study throughout rather than only at the end.

Background

Institutionally-led research often contributes to "research fatigue" when communities are consulted and studied without tangible benefits or power-sharing. Communities facing intersecting deprivations often experience participation demands without adequate resources. Research instruments (e.g., suveys, topic guides) designed without community input rest on assumptions disconnected from lived experiences, limiting validity and real-world utility. **Authentic co-production**, where community-based organisations exercise equal authority to academic institutions, can enhance validity and foster trust. The PrEP-Position study tested whether **equitable co-leadership could produce rigorous, contextually grounded data while ensuring meaningful engagement and accountability to community-defined priorities.**

Methods

- PrEP-Position was a multi-phase UK study **exploring PrEP knowledge, use, and delivery preferences among underserved communities.**
- The study was co-produced by Queen Mary University of London, Sophia Forum, and an external evaluator, with oversight from a 9-member Steering Group from minoritised communities.
- Sophia Forum led community engagement and recruitment, while the Steering Group guided all phases of the study.
- Using a convergent mixed-methods design (online survey, qualitative interviews, and prioritisation survey), the study ran from August 2025 to January 2026 and included simplified language, multilingual support, and hybrid engagement options.

Results

The study successfully enrolled 264 (Table 1) survey participants and conducted 34 (Table 2) qualitative interviews, specifically reaching groups underserved by PrEP.

Table 1.

SURVEY PARTICIPANT DEMOGRAPHICS (n=264)		
Disaggregated by Marginalised groups and Ethnic/Racial Identity		
MARGINALISED GROUPS	N	%*
Racially minoritised cis/transgender women	83	31%
Sex workers	53	20 %
Non-binary/transgender people	47	18%
Other racially minoritised heterosexual men	35	13%
Black heterosexual men	32	12%
Recent migrants	29	11%
People who inject drugs (PWID)	9	3%
Racially minoritised MSM	6	2%
Individuals experiencing insecure housing	5	2%
BY ETHNIC/RACIAL IDENTITY	N	%
White British/Other White	84	32%
Black British/African/Caribbean	83	31%
Mixed Heritage	41	16%
South Asian	22	8%
Latina/o	19	7%
Arab/Middle Eastern	9	3%
East/Southeast Asian	3	1%
Other	3	1%
DIVERSITY METRICS	N	%
TOTAL RACIALLY MINORITISED PARTICIPANTS	180	68%

*As the groups are intersectional, individuals can belong to more than one group (e.g., transgender people include trans women again).

Table 2.

INTERVIEW PARTICIPANT DEMOGRAPHICS (n=38)		
Disaggregated by Gender Identity and Ethnic/Racial Identity		
BY GENDER IDENTITY	N	%
Cisgender Men	13	34.%
Cisgender Women	13	34%
Transgender/Non-binary	12	32%
BY ETHNIC/RACIAL IDENTITY	N	%
White British/Other White	13	34%
Latina/o	7	18%
South Asian	6	17%
Arab/Middle Eastern	3	9%
Black British/African/Caribbean	7	18%
Mixed Heritage	2	5%
DIVERSITY METRICS	N	%
TOTAL RACIALLY MINORITISED PARTICIPANTS	25	67%

- Community expertise helped adapt the methods in real time**, identifying key barriers such as digital exclusion, intrusive terminology, and low trust in institutions.
- Addressing these issues reduced participation gaps and supported the team in meeting recruitment targets.
- However, important structural limits remained, including short timelines and insufficient funding for community engagement.
- These constraints created communication gaps and limited community leadership, showing how **co-produced research can still drift toward tokenism when resources are scarce.**

Conclusion

- Authentic co-production** effectively fosters inclusion and increases research validity but remains vulnerable to institutional structures.
- Community-led research requieres flexible timelines and sustained resources for trust-building.
- This study reveals the non-linear complexity of balancing broad inclusivity with strict project milestones. **Sustaining co-production demands that funders and academic institutions re-conceptualise research timelines and resource allocation to align with the relational labour genuine partnership requires.**