

Engaging MSM Communities in HIV Self-Testing Research and Programming in Kenya: Collaborations, Tacit Knowledge, and a Community-Based Programme Science Approach

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Abstract

Background: Understanding the basic principles for achieving research outcomes that are relevant to local communities is invaluable. The process allows for building of collaborative spaces and redistribution of power in knowledge production practices. This is because members of marginalized and vulnerable communities have long been critical of a research culture that has historically failed to advance meaningful collaboration and overlooks local forms of knowledge at various phases of the research processes. There has however not been a clear framework that outlines how communities should be meaningfully engaged. Rather, substantial variations in the nature of community engagements exist across research projects, thus requiring a more nuanced approach of working with communities.

Methods: In this methodological paper, we describe how a community-based program science approach guided an interdisciplinary research project to inform the rollout of HIV self-testing (HIVST) among men who have sex with men (MSM) in three urban counties in Kenya. Community members and their research and programmatic partners collaborated through all phases of the research process including research design, data collection, and translation of research. Importantly, community researchers and policy makers also played an integral role in data analysis, going well beyond the conventional role of “community engagement” in global health research.

Results: The study created a platform that enabled meaningful collaborations across the diverse stakeholders and allowed the MSM communities to contribute to the decisions and solutions impacting on their community. Our community-based program science approach recognizes that community researchers possess tacit knowledge, a form of expertise that formally trained researchers do not have.

Conclusion: We argue that in order to fully engage with such expertise, marginalized communities must be meaningfully involved in all levels of evidence building and decision making around programs impacting their communities. We equally emphasize the importance of setting up operating norms and clear definitions of partnership roles at the initial stages of establishing collaborations. Such a move gives the community a chance to trust their capabilities and contribute more meaningfully throughout the research processes.

Contributions To The Literature

- Members of marginalized and vulnerable communities have long been critical of a research culture that has historically failed to advance meaningful collaboration and overlooks local forms of knowledge at various phases of the research processes.
- Community-based program science directly involves communities in processes of knowledge production and sustained negotiations with health and social service institutions over the life course of interventions while recognizing the importance of lay expertise and tacit knowledge.
- The description of how a community-based program science approach can guide interdisciplinary and collaborative research projects contributes to recognized gaps in the literature regarding

meaningful involvement of communities, including ascertaining how tacit knowledge from communities being researched is imperative in global health research.

Background

Members of marginalized and vulnerable communities have long been critical of a research culture that has historically failed to advance meaningful collaboration and overlooks local forms of knowledge at various phases of the research processes. Communities and researchers alike have called for the adoption of decolonizing research processes which ideally should address the issues of power imbalances and mistrust in research, while allowing for contextualized, respectful and legitimate research practices that build on community agency¹⁻⁴. For more than two decades, researchers have adopted community-based research (CBR) methods that strive toward the equitable involvement of community members, organisations, researchers and other key partners in all aspects of the research process leading to shared decision making and ownership of data between community members and academic investigators⁵⁻⁹. Although the underlying purpose and specific characteristics of CBR are somewhat contested¹⁰, CBR generally calls for community-driven projects that foster active collaboration and participation at every stage of research, co-learning between scientists and community partners, the dissemination of research findings, and tailoring of interventions that are culturally appropriate¹¹. CBR may contribute to research trustworthiness as it has been shown to not only strengthen the research process but also enhance research integrity and growth of collaborations in science as a whole, thereby increasing its relevance to the community¹²⁻¹⁴.

Notwithstanding the strengths of CBR, communities and researchers have at times challenged the overall implementation of the approach. For instance, the lack of a clear framework for implementing CBR leaves the interpretation of its principles at the discretion of the researchers, leading to different interpretations of the role of the community in research and substantial variation in the nature of community involvement across projects^{15,16}. Often, the level of community involvement stagnates significantly after seeking input from community advisory groups and in some instances training the community to collect data within their communities, but largely fails to engage community participation across the life course of the research process. Moreover, in as much as CBR is promoted as an approach that can facilitate translation and dissemination of research findings to the community, in practice, there are notable gaps in the distribution of responsibilities, particularly during the dissemination of study findings. Often, researchers focus on scientific publications while community stakeholders use the data primarily for lobbying and advocacy¹⁵. This then impacts the translation of research findings into practice as the community is likely to perceive research publications as a purely academic exercise and not incorporate the findings into programs. To address these shortcomings, Brizay and colleagues have recommended a more nuanced way of working with communities, guided by a framework outlining the role of each stakeholder in the different steps of the research process¹¹. The framework should be one that will provide for flexibility in the definition of the different partners' responsibilities based on their capacities but at the same time providing a structure to work in. They see this as a way of achieving a greater role

for community in the planning and implementation of interventions and to ensure a collaborative process of generation and uptake of research findings within routine practice ¹⁵.

Program science, a research paradigm that involves an iterative process of putting evidence generated from research into practice as well as generating evidence from the routine operation of programs, ^{17–20} can further build on the collaborative approach proposed by Brizay and colleagues ¹⁵. It involves embedding research processes into the operation of programs, so that scientific knowledge continually feeds out from and into the program context to inform strategic planning, program implementation and program management ¹⁸. Put simply, program science is the science *of* programs as well as the science *for* programs. Within program science, collaborative engagements between state health systems, local and international NGOs, funders and academic institutions are conceptualized as working in alignment toward the goal of improving the health of populations.

The integration of a CBR and program science approach has the potential to foster stronger research collaborations with communities in the production and utilization of evidence throughout the life of programs. The emerging field of *community-based program science* (CBPS) refers to the unique linking of these two complimentary research paradigms ¹⁹. CBPS directly involves communities in processes of knowledge production and sustained negotiations with health and social service institutions over the life course of interventions. Importantly, it recognizes the roles played by power and social inequalities in the unequal production of expert knowledge, and centers the importance of lay expertise and tacit knowledge ²¹. Using a case study approach, we describe a pragmatic operationalization of CBPS by drawing on a Bill & Melinda Gates Foundation-sponsored collaborative HIV self-testing study (HIVST) among men who have sex with men (MSM) in three diverse counties in Kenya.

The MSM HIVST Study

MSM shoulder a disproportionate burden of HIV in Kenya, with an HIV prevalence 4-5 times higher than that of the general population ^{22–24}. In 2018, the National AIDS and STI Control Programme (NASCOP) led a key populations mapping and size estimate exercise in selected counties that showed that there were approximately 33,000 MSM frequenting hotspots[1] in Kenya ²⁵. According to the *Kenya HIV Prevention Response and Modes of Transmission Analysis* performed by the National AIDS Control Council (NACC) in 2008, 15.2% of new HIV infections in Kenya were attributed to MSM and people in prisons²⁶. In a later study through the integrated biological and behavioural surveillance survey, MSM had a HIV seroprevalence of 18%.²⁷ However, most MSM in Kenya remain unaware of their HIV status, due to high levels of stigma, limited or a lack of MSM-friendly health services, confidentiality concerns, and a fear of blood/finger prick testing ^{28,29}.

As is the case in 53 other countries on the African continent, homosexuality is criminalized by the Kenyan penal code, a relic of colonial-era laws that were upheld by the Kenyan high court in 2019^{30–34}. While data from Kenya is limited, delayed HIV testing due to anticipated stigma is well-documented among MSM and other sexual and gender minorities in countries with a range of legal stances on homosexuality

35–39. Because of estimated high rates of MSM who are unaware of their HIV status, research has called for innovative approaches to reach individuals who are undiagnosed^{40,41}. HIV self-testing (HIVST) – a process in which an individual performs and interprets their own HIV test in a setting of their choosing – has been viewed as a promising strategy for reducing the number of undiagnosed cases of HIV among vulnerable populations such as MSM, particularly in contexts where stigmatizing social conditions are likely to result in low levels of engagement with facilities-based HIV testing services^{42–46}. Moreover, evidence shows that HIVST has the potential to improve early detection of HIV and can facilitate earlier linkage with HIV prevention and treatment services^{47,48}. In Kenya, a number of studies have been conducted on the feasibility of HIVST scale-up among serodiscordant couples and female sex workers (FSW)^{49–54}. However, evidence is extremely limited⁵⁵, on how, when, and in what contexts HIVST delivery to MSM can increase knowledge of HIV status and lead to early linkage to treatment and prevention services.

Integrating HIVST interventions with CBPS principles in which MSM are at the center of program planning and implementation ensures a platform that empowers them to contribute to decisions and solutions that impact their communities. We undertook a mixed methods CBPS research project to design and implement HIVST programs among MSM in three diverse counties in Kenya (Kisumu, Mombasa, and Kiambu). The study was initiated through a collaboration between the University of Manitoba (UM), Partners for Health and Development in Africa (PHDA), the National AIDS and STI Control Programme (NASCOP), G10 (an MSM research network in Kenya), and MSM-led community-based organizations (CBOs) in each of the three counties (Mamboleo Peer Empowerment Group (MPEG) in Kiambu, Men Against AIDS Youth Group (MAAYGO) in Kisumu, and the HIV & AIDS People’s Alliance of Kenya (HAPA Kenya) in Mombasa). The study was embedded within existing HIV and sexual health programs implemented by the selected CBOs, who run HIV prevention and treatment programs that specifically cater to MSM and therefore offered a crucial partnership for the delivery of HIVST. The details of the larger intervention study have been previously described⁵⁶. In this paper we describe the CBPS process, focusing on the specific qualitative components of the study. We integrate the requirements of public involvement that are included in the GRIPP2 checklist⁵⁷ as we demonstrate all through this paper how the MSM community and other stakeholders we actively involved in the entire research process.

[1] Physical spaces where MSM meet other sexual partners.

Methods

Developing a CBPS Approach for the MSM HIVST Study

Setting the research agenda within existing programs

In 2018, after examining program data that revealed low HIV testing rates among MSM, NASCOP and University of Manitoba initiated discussions between partners on the potential of initiating a CBPS HIVST study among MSM. Kenya has a history of strong leadership among organizations serving MSM,

including a national body (G10) that leads research among LGBTI communities. NASCOP, in partnership with UM and PHDA, approached G10 and its partners in Kiambu, Kisumu and Mombasa of which G10 identified three partner CBOs to participate in the project. The CBOs each had extensive experience in program implementation and a large program reach. We developed a formal partnership with each CBO, initially through the exploratory research phase and then through the entire research process from protocol development/research design, data collection, data analysis, and dissemination/translation of findings. We began by setting up a three-month exploratory process to assess the feasibility of the study. Based on the successful completion of the preliminary assessment phase which entailed virtual mapping⁵⁸ (assessing MSM use of virtual platforms such as geosocial networking and other social networking applications to find sexual partners) and consultations with the community to assess feasibility of partnerships, we negotiated formal, 12-month partnership agreements with clear roles and defined responsibilities for all collaborators at all the levels of the study. After consensus and consultation, UM was given the responsibility of overseeing the evaluation, the CBOs took the role of study implementation, while NASCOP was given the role of policy and advocacy. Point persons from each institution were selected and formed a core team of 16 members for oversight and decision-making. Though leadership roles were clearly divided, supportive roles were also defined. For instance, while UM served as the lead on the evaluation, the CBOs participated in the design of the study, provided direct guidance and support to UM by identifying community researchers (CRs), supported and monitored data collection, supported analysis and interpretation of the data, and used the data for improvement of programs. Similarly, though CBOs led the implementation, UM and NASCOP contributed to the study design by co-designing the intervention design, conducting capacity building on HIVST and modes of distribution, training of CRs in data collection and analysis, and designing a monitoring system. In addition, UM and its local partner PHDA had a representative based in each of the participating counties who then became the point person for project-related discussions and decision-making. Regular updates occurred through monthly report sharing, face-to-face meetings, email updates and more informal approaches. Importantly, UM, PHDA and the CBOs supported NASCOP in the dissemination by sharing study findings in key forums such as the Kenya's key populations community of experts forum, and advocating with the different county governments to share study findings and organize collaborative activities.

Study Design and Protocol Development

Collaborative strategic planning is central to CBPS. It centers on ensuring all key stakeholders in a study are actively involved including in the design and the development of a project. The process allows for the integration of tacit knowledge and the adaptation of local contexts in the design of projects. In our case, to ensure active participation of the MSM community and all other collaborating partners in the entire research process, a protocol development workshop was organized. The workshop saw all the collaborating partners come together in order to establish the research questions, the rationale of the study project, and strategies that would be relevant in the conduct of the study. As such the aim of the workshop was for each of the collaborating partners including the MSM community to develop a study protocol to evaluate a community-based HIV self-testing delivery strategies on reducing undiagnosed HIV

infection, and improving linkage to prevention and treatment services, among men who have sex with men in Kenya.

Baseline Qualitative Exploratory Study

Recruitment and Training of Community Researchers

As part of the ongoing active involvement of the community in the study, the CBOs, in collaboration with the PHDA field coordinators and the qualitative research coordinating team (which included the first, second and the last author), recruited CRs from within their membership who would then be involved in the qualitative data collection and analysis processes throughout the study period. Four CRs from each of the three participating sites were recruited, for a total of twelve CRs. For the baseline qualitative exploratory phase, the CRs, together with their respective community study supervisors, were taken through a participatory training on key principles in research ethics⁵⁹ and qualitative research methodology by the first, second, and last author. In the same forum, the CRs participated in the framing of the interview questions and development of the data collection tools, including the interview guide and demographic form. In order to have precise questions that could be asked in different local languages across the three participating sites and to troubleshoot for potential points of confusion for participants, the CRs practiced the questions through multiple role-play sessions and refined them accordingly. For example, during the first role play session a CR from Mombasa asked about the impact of bleeding gums on the test. The second author captured this exchange in a fieldnote included below.

While the community researchers practiced using the interview guide with one another, Fatima raised her hand and asked, "What happens if their gums are bleeding and there is blood on the stick?" The coordinating research team initially thought that this would not present a problem as the test is designed to identify antibodies in saliva. However, as we carefully re-read the clinical information on the back of the instructions, we discovered that blood on the test strip can indeed lead to an invalid test. This also raised the question among some community researchers about how to explain to participants that though the test works by identifying antibodies in saliva, HIV cannot be transferred through saliva. [The last author] stopped the role-playing exercise to stress that this would be an instance in which the community researcher has an ethical responsibility to ensure that the participant does not leave with incorrect information. After some discussion, the interview guide was edited to ensure that when the community researcher explains the oral swab, they also explicitly state that HIV is not transmitted through saliva and to remind the participant that they can ask more detailed information from the clinician after the interview process.

Sampling

Before the CRs began conducting interviews in their respective counties, the first, second and last author together with the PHDA field coordinators visited each of the respective sites where they advised CRs and observed them as they created their own sampling tree (see Figure 1). Using pseudonyms, they listed their potential participants while considering both those enrolled and not enrolled in programs, as well as

ensuring representation from different socio-economic backgrounds. Inclusion criteria included men reporting having had sex with another man or transgender woman in the past 12 months, being 18 years or older, and willing to be followed over a period of one year to participate in baseline, midline and endline interviews. Each CR team generated a list of potential participants who met the inclusion criteria from within their own social networks. Peer educators or outreach workers in the CBOs were not eligible to participate in the interviews. Participants were selected to ensure equal age distribution, as well as to account for the experiences of MSM who were enrolled in CBO programs and those who were not. To ensure representation of different socio-sexual networks, CRs also selected participants based on their involvement in sex work and their socio-economic status. Part of this process was captured by the second author in the fieldnote below:

When introducing the concept of sampling to the Mombasa team, [the last author] used the metaphor of cooking rice. "In order to know if it is cooked well you need to taste different spots in the pot. Sampling in research is the same idea," he explained. We asked the community researchers to start by listing the "different kinds of MSM" in Mombasa. They listed: age, sex work, enrolled [in MSM programming] vs. not enrolled, and "class". The last author mentioned that this is essentially a conversation about diversity, that while they are all MSM, there are characteristics that make them different.

Conducting the interviews

Between May and August of 2019, the CRs interviewed a total of 72 participants. The interviews explored participants' perceptions on the HIVST technology, and their opinions on the best strategies CBOs could use to deliver HIVST to the MSM community. With consent from all participants, the interviews were audio recorded, and later translated [when necessary] and transcribed verbatim in English by trained community members. The study procedures were approved by the research and ethics review board at the Kenyatta National Hospital in Kenya and the University of Manitoba, and all participants provided written informed consent.

Participatory Data Analysis

One key principle of CBPS-driven interventions is having communities actively participate in the production of evidence throughout the life course of the intervention. However, more often than not, studies that profess to follow a CBR approach fail to directly include community participation in the data analysis process 60–62. Engaging community members in the analysis and interpretation of research data ensures communities' perspectives, knowledge, and contributions are authentically included. The process yields rich analytic insight and contextualization that fosters the translation of findings into local community health practice. Local knowledge gained through years of experience and practice as a member of the community – what is referred to as tacit knowledge – is an integral dimension in the interpretation and translation of findings into practice within the local context 63. We therefore undertook a deliberate move to involve the CRs and their CBOs study coordinators in a collaborative analysis process of the qualitative interview data. The team participated in a process of meaning-making that had multiple steps 64,65 .

Training on Thematic Analysis

Under the guidance of a locally-based qualitative research coordinator (the first author) and two senior medical anthropologists (the second and final authors), CRs were taken through a two-day training to learn how to conduct basic thematic analysis from an interpretivist perspective 66. Specifically, using different facilitation skills and simplified visual aids such as videos (<https://www.youtube.com/watch?v=phXssQBCDIs>) and samples of already analyzed transcripts, the team learned about reviewing and familiarization with the transcripts, coding, memo-ing, data interpretation, and composing findings section. Three transcripts from each of the three participating sites were picked for the participatory data analysis exercise.

Familiarization and Coding

To embark on the analysis process, the CR team undertook a deep reading of a set of transcripts in small groups in order to familiarize themselves with the contents of the transcripts. They then provided an overview of the data to the larger research team before returning to their small groups to begin a more detailed analysis of the individual sections of the transcripts. At this stage, the CRs read through the transcripts a second time and took initial notes. For this first step, team members were put in smaller groups composed of both the CRs and study coordinators. The first, second, and final authors supported the groups by listening to the various discussions and asking questions that would be relevant to aid the analysis process. The purposeful grouping in turn allowed for a variety of perspectives to be represented during the research team's early interaction with the transcripts and ensured a cross-mingling of ideas. For example, one CR from Kisumu directed his small group's attention to the complex security concerns that the kit posed. A fieldnote captured by the second author details this exchange:

While reviewing a section of the transcript, John turned to [second author] and [fourth author] and said that the interviewer "missed" something. While being probed for their concerns about the HIVST, the participant had briefly alluded to security concerns, expressing the potential for the kit "outing" users as they have become increasingly associated with the [MSM] community. John felt that the CR conducting the interview should have asked for more details about this and explained that several of participants he had interviewed had expressed similar security concerns. As the kits are marketed towards sexual and gender minorities, he worried that the mere presence of the kit might make users vulnerable to blackmail. [The fourth author] explained that the same thing happened when pre-exposure prophylaxis [PrEP] was marketed towards the community, making CBOs serving the community more visible than they had been previously. "Now they know where gay men are and where they access services," he explained.

During the coding process, the CR teams highlighted salient segments of the transcript and allocated a single word or short phrase to describe the content. The transcripts were printed with wide margins on the right side to create space to write codes on the transcripts.

Code Grouping and Definitions

During the next level of analysis, the small groups listed all the codes (child codes) and identifying related codes that they then grouped together to create parent codes. The parent codes were then presented to and discussed with the entire team. The discussion helped the team to begin to see some commonalities in the data and relationships across the different data sets. The members regrouped into three larger groups representing their three study sites. The CRs and the study coordinators then developed definitions for each parent code. Figure 2 shows a sample of listed codes from one of the groups.

Reconciling Coding Schemes and Composing Findings Sections

Next, the training facilitators reviewed the grouped codes and definitions in order to create a sample guide. The sample included the parent code, the definition of the code, and excerpts from the transcripts. Retaining the same site level groups, members used a laptop to extract excerpts from the three transcripts from their respective sites and assigned them accordingly to the defined parent codes. Each group then selected six parent codes they considered a priority and wrote up summaries bringing out the overall message of each of the parent codes that they would want to convey to program implementers and policy makers. From the combined codes, the team prioritized the following parent codes: 1) attitudes towards HIVST kits, 2) perceived advantages of using HIVST kits, 3) barriers that would impact on use of HIVST kits, 4) HIVST demand creation and advocacy, 5) service delivery approaches, and 6) role of health facilities. To conclude the analysis exercise, the groups exchanged their write-ups for critical review and the feedback provided to each site level group was used to improve the write-up of the findings.

Dissemination of study results

A key feature of CBPS is the dissemination of study findings with community members and the active involvement of the community partners in the process. This is an approach therefore that we embraced in the implementation of our CBPS study. The MSM community were actively involved in the dissemination of study findings that went beyond the ordinary scientific publications as is often the case. We built on both existing and new structures in order to share the findings. For instance, the community was largely involved in the sharing of the findings at the counties and at national level through various forums such as the key populations committees of experts' forums and other relevant meetings. Also, the community wrote a first authored paper that shared with a wider audience on the efforts the community put to reach the MSM with HIV testing services amid Covid-19.

Results

Application of Findings in the HIVST Intervention

The research team's findings on how to implement a community-led delivery of HIVST for MSM informed the intervention such that the CBOs included HIVST into their ongoing HIV prevention and treatment programs (for further details on the findings see Thomann et al., forthcoming). The data analysis process concluded with an agreement that individual site teams would come together at their respective organizational level, while considering their respective contexts, to review findings and to assess what

could be integrated into the HIVST intervention for MSM. For instance, in the analysis, participants from across the sites had suggested MSM-specific social events, alongside a need for sensitization and networking at physical hotspots and virtual platforms, as a means to increasing uptake of HIVST kits. Emmanuel, a 37-year-old gay man from Kisumu, explained how MSM can be reached in groups and sensitized about HIVST.

...they can have theme activities that they partake like they have movie Mondays where people come to watch a movie, that is. ... a movie that you know has a gay-related theme or health-related or HIV health-related theme; so, they can bring their clients in those themed days, and they can be educated on that [HIVST].

The CBOs put in place mechanisms for holding MSM-themed social events that were designed to fit their specific contexts. For instance, in Kisumu, MAAYGO held what they referred to as an “HIVST Party” targeting their community members in a hotel and integrated themed activities such as singing, poetry, spoken word and run-way modelling. In Kiambu, MPEG held their MSM-themed event to promote HIVST at local entertainment clubs known to be frequented by MSM in the area. Similarly, mobilizations for the uptake of the kits occurred at physical spots frequented by MSM, as well as through varied social and dating virtual platforms such as Facebook pages, WhatsApp groups, Planet Romeo, Badoo and Grindr, among others.

The site-level analysis of the data by the different site teams provided instrumental findings that informed programs on the specific considerations they needed to make in the design of the intervention. The team from Mombasa, for instance, concluded from the analysis process that reaching some MSM in their region with HIVST kits would be deterred by the strong religious ties in the area and high levels of HIV-related stigma from religious leaders and the local community. During his interview, Bruce, a 21-year-old gay man from Mombasa, explained the deep-rooted HIV-related stigma within religious communities.

In Mombasa, because of churches, mosques, you cannot go just anywhere distribute [HIVST kits], they will look at you ... and at the streets when you just say we are here to teach you about HIVST kit, when you just name, the word HIV, people will be like looking at you, they will be surprised to hear the name, because HIV to some is like they believe that when I am infected with HIV that's the end of me.

In order to pro-actively address these stigma-related concerns, the Mombasa team engaged key religious leaders and other community opinion leaders from the area for a sensitization session on HIVST among MSM, ahead of distributing the HIVST kits. This provided a platform to initiate a partnership that would begin to address HIV-related stigma directed toward the MSM community.

Another area considered for HIVST interventions was the integration of MSM-targeted health services within government health facilities. Most participants interviewed who were not members of any of the MSM programs reported they would not want to be identified as an MSM or be associated with the MSM-led organisations and preferred a distribution approach that would allow them to get the kits from

government health facilities. Evans, a 35-year-old gay man from Kisumu, justified why he would prefer a government facility:

I have never had a problem taking services at the government hospital, yeah only if it's a sensitive issue like maybe anal STIs, that one I cannot go to the government hospital but when it's just the, the normal health routine like maybe I want to go for HIV testing and counselling or maybe I need to get some condoms, that one I don't have a problem, because usually when I go to access health in any health institution, I go as a Kenyan who has a right to access health. I don't go as MSM.

Based on this, all three sites worked on context-specific approaches that would allow them to collaborate with select government health facilities within their respective counties. In Kisumu for instance, apart from their clinic operating within the CBO premises, the organisation negotiated and was assigned space at one of the government facilities in order to offer HIV prevention and treatment services including HIVST kits to their members.

Alongside the integration of study findings to ongoing interventions, it is important to note the implementation of the intervention was equally an iterative process which involved several revisions being made to the intervention strategies as findings emerged. For instance, as captured in the ethnographic field notes, in Mombasa, because of COVID-19, they engaged a motorbike rider to ensure continuity of distribution of the HIV self-testing kits to the MSM community within the target area. Also, in all the sites, demand creation through the social media and other virtual spaces was intensified.

Discussion

Implementing the HIVST intervention while following the principles of CBPS promoted meaningful collaborations and a mutually empowering process across the diverse stakeholders. Specifically, the process enabled the community to gain the confidence, authority and capability to meaningfully contribute to the entire research process. Active participation of the community in all phases of the research project, including shaping the direction of the study and the analysis of findings, realizes the central tenants of community-based research 68,69. Such inclusion promotes co-learning and empowers the community to steer social change, and enables the researchers to implement studies that are grounded in real contexts 70–72. The CBOs implementing the HIVST intervention, by virtue of playing an integral part in the analysis process, were able to translate the findings to allow the integration of HIVST in their ongoing HIV prevention and treatment programs. In this way, CBOs readily adopted the qualitative evidence into their program activities.

While meaningful community inclusion is a key component of CBPS projects, as is the case with other forms of CBR, there are inherent power imbalances that exist between the 'researchers' and the 'community'. Even with well-designed and well-intentioned studies aiming for equal partnerships and sharing of power in the co-production of evidence, disrupting traditional power hierarchies can still be challenging 73. In our example, the fact that UM was the main applicant to the research funding and interacted with the donors, while the CBOs were not aware of the UM's budget but named as co-

investigators in the study, helped maintain the traditional power hierarchies. As a result, we observed that the CRs frequently waited or asked for direction from the 'researchers' rather than taking the lead in the discharge of their roles. In addition, the community always expressed their gratitude for the opportunities that the 'researchers' provided to them, while negating to acknowledge the opportunities that they themselves provided to the researchers, including the platform in which the research took place. It remains a challenge to create a sense of 'equal' partnership among community and academic researchers in studies, with the unique knowledge and valuable contribution by community often failing to be significantly recognized by both the community themselves and other members of the research team. In our project, efforts were made by the researchers to organize the research training sessions in a way that was participatory to facilitate 'equal' and bi-directional learning for both the community and the researchers.

Having community members as part of the research team has been promoted as one way to help address researcher-researched power imbalances, potentially leading to higher levels of community acceptance and the community actively contributing their local, specialized knowledge during study implementation^{5,74}. There has been increasing attention given to building balanced partnerships in research between researchers and marginalized communities^{12,15,75}. In some instances, researchers and community activists have together launched advocacy projects as a way to ensure that members of the MSM community are actively engaged in research studies. This is done with the primary aim of strengthening the capacity of the community, as well as establishing the legitimacy of the research team as a whole such that research conducted is acceptable by the community^{76–80}.

As described earlier, through the MSM-led CBOs, community members were recruited as researchers from within the membership of the CBOs. Although the community researchers were carefully trained on research ethics and performed several role-playing exercises based on potential scenarios in the field; in practice, dealing with challenges related to the dual role of 'researcher' and 'community member' at times caused more discomfort than envisioned. When doing the interviews, the community researchers were 'out' about being part of the MSM community, a move that was thought would foster a level of trust with the participants. However, some community researchers reported receiving sexual propositions from their participants which made the progress of their interviews challenging and might have affected the nature of the responses from the participants. Ibáñez-Carrasco and colleagues recommend research teams prepare peer researchers for ongoing changes that may occur in their roles, identity and experience.⁸¹ In our context, the team discussed such potential occurrences and agreed it was appropriate to discontinue an interview with a participant that made them feel uncomfortable, or to clearly explain to the participants the boundaries between their work and social lives. This helped the CRs to maintain a sense of professionalism needed to safely and comfortably complete their work, while interacting with their peer participants.

Conclusion

A CBPS approach aims to ensure that communities are not only ‘collaborators’ but ‘colleagues’ in the production of evidence and the overall implementation of the study. We emphasize the importance of creating operating norms and clear definition of partnership roles well in advance and before embarking on the study as an important step to take. We observed that such a move in CBPS gives the community a chance to trust their capabilities and more equally contribute to the implementation of the study. Over and above the fact that we observed power imbalances play out in the implementation of our CBPS HIVST study, power hierarchies were effectively challenged through clear role definitions set up during the study design. All partners were part of the early discussions about the study and, as a result, were clear on their roles in the HIVST implementation and integration of study findings into existing community programs. Other researchers taking up CBPS as an approach should consider allowing time for building meaningful relationships with the relevant communities and other stakeholders as a way of beginning to build a platform where all partners feel valuable to contribute their knowledge and expertise.

Abbreviations

AIDS: Acquired Immune Deficiency Syndrome, CBO: Community-Based Organization, CBPS: Community-based programme science, CBR: Community-based research, CR: Community Researchers, FSW: Female Sex Worker, HAPA Kenya: The HIV & AIDS People’s Alliance of Kenya, HIV: Human Immuno-Deficiency Virus, HIVST: HIV Self-Test, LGBTI: Lesbian, Gay, Bisexual, Transgender, Intersex, MAAYGO: Men Against AIDS Youth Group, MPEG: Mamboleo Peer Empowerment Group, MSM: Men Who Have Sex with Men, NACC: National AIDS Control Council, NASCOP: National AIDS and STI Control Programme, NGO: Non-governmental organisations, PHDA: Partners for Health and Development in Africa, UM: University of Manitoba.

Declarations

Ethics approval and consent to participate

The study obtained approval from the institutional review boards of the Kenyatta National Hospital - University of Nairobi, Kenya (P557/08/2018) and the University of Manitoba–Health Research Ethics Board, Canada (HS22205). All participants provided written informed consent.

Consent for publication

All participants provided written informed consent before participating in the study, which included consent to publish anonymous quotes from individual participants.

Availability of data and material

The datasets that support the findings of this study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

PB, RL, BK, MT, LL, HM, KO, SK, MK, MO, MN, and JM participated in the design of the study, designed the qualitative and quantitative study and its instruments and drafted the manuscript. BK, RL and MT trained the community researchers in qualitative data collection and analysis. RL, MT, BK, KO, SK, MO, MN analyzed the qualitative data. PB, HM, JM, MO, MN designed the intervention. BK drafted the first draft of the manuscript. MT, LL, PB, RL reviewed the manuscript. All authors have read and approved the final manuscript.

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Figures

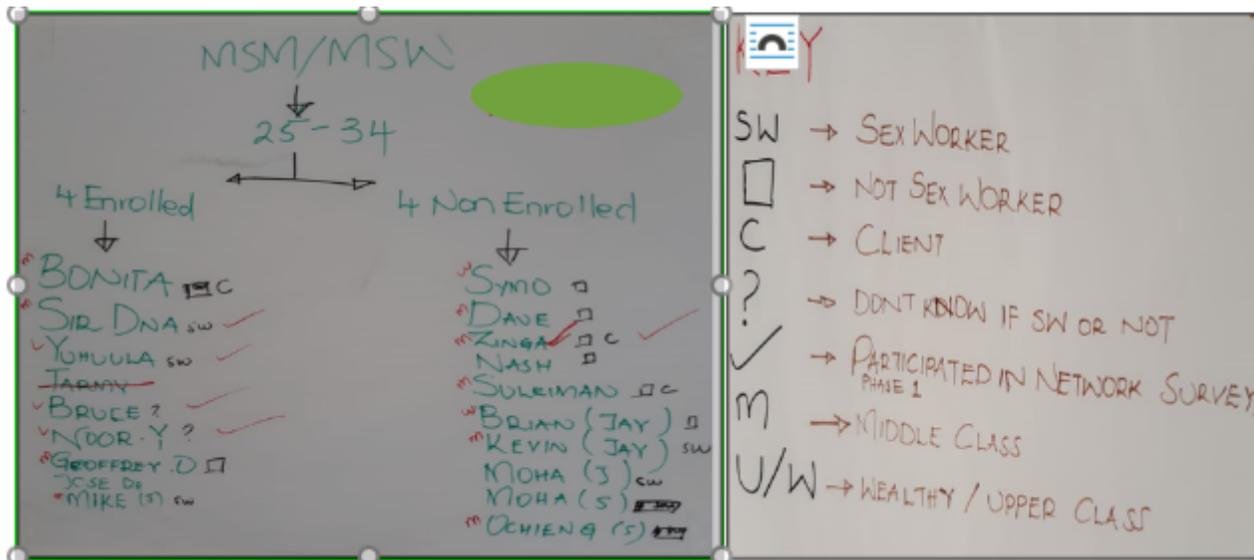


Figure 1

Example of a sampling tree with pseudonyms developed by the community researchers at their respective sites

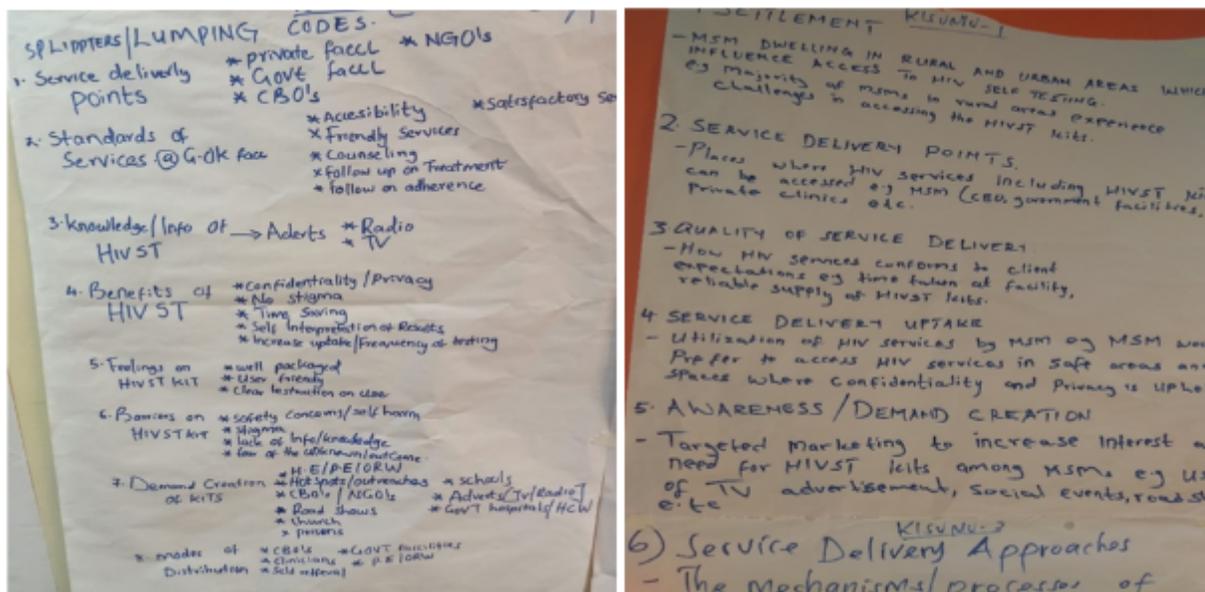


Figure 2

Sample of child codes to make parents codes and consolidated code definitions