An iterative approach to respondent driven sampling (RDS) using community-based participatory research (CBPR) among men who have sex with men (MSM) and female sex workers (FSWs) in Swaziland


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Abstract

• Due to the illegal and highly stigmatized nature of these populations, community-based participatory research methods were employed in Swaziland’s first bio-behavioral surveillance effort of MSM and FSWs.
• Community-based participatory research is a way of encouraging community ownership of research by involving community members at all stages of the research process, from conception to analysis.
• Initially, the same strategies were used for both populations, but economic and social differences became clear and approaches shifted based on community response and needs.
• Meaningful and continuous involvement of community members can address practical challenges and help to ensure study success when using RDS among hidden or socially marginalized populations.

Introduction

In January 2011, the Swaziland Ministry of Health, Johns Hopkins School of Public Health, PSI, and USAID implemented an integrated bio-behavioral surveillance survey among MSM and FSWs using RDS. Both MSM and FSW behaviors are illegal and highly stigmatized in this setting. Accrued participants enrolled in the study through informed consent, completed an interviewer-assisted survey, and tested for HIV and syphilis. CBPR methods were used to reach, educate, and involve members to actively participate and drive the research so as to increase visibility of the health and social needs of these populations both from within their communities and to the nation at-large.

Methods

Study investigators similarly engaged LGBT/MSM community groups and FSW support networks in formative research process (Figure 1):

1. Informal community engagement to introduce study and ascertain engagement design.
2. Forming community-member elected Community Advisory Committee (CAC), one for LGBT/MSM and one for FSW that met separately and independently of each other.
3. CAC members provided crucial community feedback, concerns, and advice for the research team.
4. Research team disseminated study updates broadly through CAC.
5. Study investigators directly interacted informally with community members.

Results

LGBT/MSM

• Preferred meeting in private homes of community members
• In the beginning, MSM accrual was slow. The CAC gathered feedback and discovered MSM were uncomfortable with sharing research; MSM accrual picked up after FSW accrual completed and site became dedicated to MSM
• There was one central CAC, which provided efficient, broader community feedback
FSWs

• Comfortable with meeting in public spaces
• Efficient accrual due to pre-existing networks
• There were four regional CACs, which provided region-specific and varying feedback

Both Populations

• Actively volunteered to be engaged and integrated into study design and implementation
• Named the study “Vakala” (Be Heard)
• Gave detailed feedback on community mobilization, crisis communication strategy, design of site operations, and sat on study hiring panel

Conclusions

After many hurdles, the study reached recruitment targets while continuously engaging community members. This engagement also led to strengthening ties between community members and civil society, agencies, and ministries.

The engagement of the FSW and LGBT/MSM communities was crucial to reaching accrual targets, laying the groundwork for subsequent interventions, and, most importantly, providing a platform for them to have a voice and be heard for their own health, social, and economic needs.

Community-based participatory methods are not a means to an end. Community members should be engaged, trained, and empowered to identify, explore, and analyze the issues they face in their daily lives in order to provide sustainable development after the life of a particular research study.

Future research and programs should use these methods to incorporate FSW and LGBT/MSM populations in HIV prevention, treatment, and care in an iterative, community-centered approach.

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Figure 1 Community-Based Participatory Research Engagement Strategy: A Conceptual Framework

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