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Working with economically vulnerable women engaged in sex work: Collaborating with community stakeholders in Southern Uganda

Proscovia Nabunya^{a,b}, Joshua Kiyingi^{a,b}, Susan S. Witte^c, Ozge Sensoy Bahar^{a,b}, Larissa Jennings Mayo-Wilson^d, Yesim Tozan^e, Josephine Nabayinda^b, Abel Mwebembezi^{b,f}, Wilberforce Tumwesige^{a,b}, Barbara Mukasa^g, Rashida Namirembe^a, Joseph Kagaayi^h, Janet Nakiguddeⁱ, Mary M. McKay^a and Fred M. Ssewamala^{a,b}

^aBrown School, Washington University in St. Louis, St. Louis, MO, USA; ^bInternational Center for Child Health and Development, Washington University in St. Louis, St. Louis, MO, USA; ^cSchool of Social Work, Columbia University, New York, NY, USA; ^dDepartment of Applied Health Science, School of Public Health, Indiana University, Bloomington, IN, USA; ^eSchool of Global Public Health, New York University, New York, NY, USA; ^fReach the Youth (RTY) Uganda, Kampala, Uganda; ^gMildmay Uganda, Kampala, Uganda; ^hRakai Health Sciences Program, Kalisizo, Uganda; ⁱDepartment of Psychiatry, School of Medicine, Makerere University College of Health Sciences, Kampala, Uganda

ABSTRACT

Economically vulnerable women engaged in sex work (WESW) comprise one of the key populations with higher prevalence of HIV globally. In Uganda, HIV prevalence among WESW is estimated at 37% and accounts for 18% of all new infections in the country. This paper describes the strategies by which we have engaged community stakeholders in a randomised clinical trial aimed at evaluating the efficacy of adding economic empowerment components to traditional HIV risk reduction to reduce the incidence of STIs and HIV among WESW in Uganda. We demonstrate that stakeholder engagement, including the engagement of WESW themselves, plays a critical role in the adaptation, implementation, uptake, and potential sustainability of evidence-based interventions. To our knowledge, this is the first study to utilise stakeholder engagement involving WESW in Uganda. Researchers working with hard-to-reach populations, such as WESW, are encouraged to invest time and resources to engage key stakeholders through a full range of collaborative activities; and ensure that research is culturally appropriate and meets the needs of all stakeholders involved.

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1. Introduction

Over the past decade, the acceleration of the global response to HIV has resulted in significant achievements. Increased access to antiretroviral therapy (ART) and prevention of mother to child transmission of HIV (PMTCT) services have contributed to the decline in HIV incidence rates globally, with a 33% reduction in AIDS-related deaths (UNAIDS, 2019). However, the global HIV burden is still substantial, with an estimated 37.9 million people living with the disease, and 1.7 million newly diagnosed in 2018 (UNAIDS, 2019). This burden is disproportionately concentrated

CONTACT Proscovia Nabunya  nabunyap@wustl.edu  Brown School, Washington University in St. Louis, 1 Brookings Drive, St. Louis, MO 63130, USA

in sub-Saharan Africa (SSA); more than 70% (about 27.8 million) of all people living with HIV live and two-thirds of all new infections occur in this region (UNAIDS, 2018, 2019).

More than half of all new HIV infections are among key populations and their sexual partners, including men and women engaged in sex work, men who have sex with men, and individuals who inject drugs (Baral et al., 2012). While these subgroups make up a small proportion of the general population, they have extremely high risk of acquiring HIV, estimated at 12–22 times higher compared to the general adult population (UNAIDS, 2018). Similar to other SSA countries with high HIV burden, Uganda reports high rates of HIV prevalence among women engaged in sex work (WESW), estimated at 37% and accounting for 18% of all new infections in the country (Uganda AIDS Commission (UAC), 2019). In Kampala, the capital city, the HIV prevalence among WESW is estimated to range between 31% and 44% (Hladik et al., 2017; Vandepitte et al., 2011). Therefore, major prevention efforts, including HIV risk reduction services, are needed to reduce the incidence rate of HIV, especially among WESW, if we are to make progress towards achieving the United Nations' goal of eliminating AIDS as a public health threat by 2030.

A critical piece for the success and sustainability of prevention/intervention efforts is community engagement. In this paper, we describe the strategies by which we have engaged community stakeholders in a randomised clinical trial aimed at evaluating the efficacy of adding economic empowerment components to traditional HIV risk reduction to reduce the incidence of STIs and HIV among WESW in Uganda.

2. Factors associated with high HIV prevalence rates among WESW

A combination of behavioural, biological and structural factors heightens the risk of HIV infection among WESW (Scorgie et al., 2012; Shannon et al., 2015). Behavioural factors include having multiple and concurrent sexual partners, inconsistent condom use, duration of sex work and type of sexual activity (Baral et al., 2012; Dunkle et al., 2005; Wang et al., 2007). Biologically, women are eight times more likely to contract HIV in a single sexual act with an infected male partner than men are with an infected female partner (Cwikel et al., 2008). The high prevalence of sexually transmitted infections (STIs) among WESW (Cwikel et al., 2008; Dunkle et al., 2005) and the synergistic relation between HIV and STIs, further compound their risks to HIV infection in this population (Cohen, 1998). These risks may also be exacerbated by the intersection of injecting drugs and alcohol use (Chersich et al., 2014, 2009; Strathdee et al., 2008). Studies have demonstrated a high prevalence of injecting drug use among WESW in various settings (Strathdee et al., 2008). Moreover, WESW may face additional risks associated with sharing needles, multiple sexual HIV infected partners, and unsafe sex (Strathdee et al., 2008).

Structural level factors, including poverty, stigma and discrimination associated with sex work, gender inequality, physical and sexual violence, and social exclusion (Argento et al., 2011; Onyeneho, 2009; Simić & Rhodes, 2009), increase the risk of HIV infection among WESW. In SSA, studies show that WESW experience intense stigma, discrimination, and consequent social marginalisation, which in turn deepen their vulnerability to HIV infection (Dunkle et al., 2005; Scorgie et al., 2012; Udoh et al., 2009). The stigma ascribed to sex work may keep WESW from seeking HIV/STI treatment and prevention services, including testing, pre- and post-exposure prophylaxis, access to condoms, and ART treatment (Dunkle et al., 2005; Richter et al., 2010). In addition, the criminalisation of sex work prevents WESW from reporting violence to law enforcement or seeking legal counsel following sexual violence (Arnott & Crago, 2009). Criminalisation affords police enormous power over WESW and exposes them to extortion, beatings and other forms of violence, including sexual coercion and assault (Decker et al., 2015; Deering et al., 2014; Footer et al., 2016), taking away their power to seek healthcare services. As such, scaling up effective HIV prevention strategies among WESW will depend fundamentally on protecting the rights of these vulnerable women, reversing harmful government policies, and setting appropriate priorities that address the needs of WESW.

The aforementioned risk factors make it difficult to reach WESW with prevention and treatment services, even when resources are available (Coetzee et al., 2017). Moreover, these factors are further compounded by challenges associated with engaging vulnerable populations in general, such as difficulties associated with recruitment and sustained participation due to mistrust and feelings of exploitation (Magnani et al., 2005; Remple et al., 2007), as well as high levels of mobility. Even in situations where WESW agree to utilise prevention and treatment services, retention rates tend to be low, mainly due to the limited number of facilities that cater to their specific needs, and their high mobility (Oransky et al., 2009). These challenges have increased calls to involve WESW in programme development and research processes to improve clinical care (Gerassi et al., 2017; Van der Meulen, 2011).

3. Role of stakeholder engagement in research with WESW

Stakeholder engagement has been documented as a critical component in improving research implementation, procedures, and outcomes (Goodman & Sanders Thompson, 2017; Shaver, 2005). Stakeholders are broadly defined as individuals or groups, including organisations or communities, that have a direct interest in the process or outcomes of the research study (Boaz et al., 2018; Concannon et al., 2012). These may include research participants, members of local communities in which a research study is being conducted, government organisations, civil society organisations (CSOs), including non-government organisations (NGOs), as well as funding agencies that shape the research process (Concannon et al., 2012).

Stakeholder engagement in research is defined as the process through which those responsible for implementing the research study build transparent, meaningful, collaborative, and mutually beneficial relationships with interested or affected individuals or groups (Concannon et al., 2012). Studies have documented a broad range of activities in which stakeholders can engage, based on their skills, attributes, and capacity as well as the needs of the research team (Day et al., 2018). Indeed, stakeholders may inform the research process at various stages, including during conceptualisation, identification of research questions, data collection, analysis, and interpretation, and dissemination and uptake of research findings (Concannon et al., 2014). A systematic review conducted by Day and colleagues (2018) to examine stakeholder engagement for HIV clinical trials identified 25 distinct purposes for which stakeholder engagement was undertaken, including: understanding factors affecting study recruitment, enhancing the informed consent process, informing the ethical conduct of research, developing trial tools and developing stakeholder engagement strategies for the trial. However, studies are more likely to engage stakeholders during the earlier stages of the research process, as opposed to the later stages, including interpretation and dissemination of research findings (Day et al., 2018).

In HIV research, careful consideration is required due to the unique physical, psychological and social vulnerabilities associated with HIV infection (De Santis, 2008), as well as subsequent ethical obligations towards study participants (Mikesell et al., 2013; Rennie & Sugarman, 2010). Among hidden and hard-to-reach vulnerable populations, such as WESW, it is important to consider participants' safety, while also maintaining high methodological rigour and utilising various sampling strategies to be as inclusive as possible of their varying experiences (Makhakhe et al., 2018). As such, engaging stakeholders who are aware of the needs and priorities of their constituents eliminates barriers to research participation and results in research that is more sensitive to cultural norms (Holzer et al., 2014; Makhakhe et al., 2018), and effectively responds to stakeholders' needs and perspectives (Brizay et al., 2015; Corbie-Smith et al., 2012). Therefore, designing studies in collaboration with stakeholders, including WESW and other experts in the field, is critical in ensuring the safety of participants, high levels of participant recruitment and retention, and overall success of the research study (Gerassi et al., 2017).

Although the importance of stakeholder engagement for HIV research is widely recognised (Kagee et al., 2020; Lo et al., 2015; Newman et al., 2015), little is known about how stakeholder

engagement strategies are being implemented and the extent to which stakeholders are included in the research process when working with WESW. Most of the studies have been conducted outside SSA (Goldenberg et al., 2015; Reed et al., 2014; Sinha, 2017). Therefore, information is limited about stakeholder involvement in research processes involving WESW in low-resource settings, such as those in SSA, where sex work is criminalised. This paper describes the community stakeholder engagement process in the implementation of a research study aimed at reducing high HIV risk among economically vulnerable WESW in Uganda.

4. Engaging community stakeholders for sustainable and impactful research among WESW: Kyaterekera Project as a case example

The Kyaterekera Project (2018–2023) is a three-arm randomized clinical trial (RCT) that evaluates the efficacy of adding economic empowerment components to traditional HIV risk reduction (HIVRR) to reduce new incidences of STIs and of HIV among WESW in the greater Masaka region of Uganda (Ssewamala et al., 2019). The study was planned for enrolment of 990 self-identified WESW, recruited from 33 comparable HIV hotspots (sites) located in 7 districts in the region, including, Masaka, Lwengo, Kyotera, Rakai, Mpigi, Kalungu, and Lyantonde. However, due to COVID-19 and resultant mitigation requirements (i.e. social distancing, lowered indoor capacity, travel bans, curfews, etc.), the study suspended recruitment in March 2020. The total enrolment up until that time was 542 WESW. The project's design and aims were therefore implemented as outlined in the previously published protocol (Ssewamala et al., 2019), briefly described below, using a smaller sample size ($N = 542$).

Women were eligible to participate if they met the following conditions: (1) 18+ years; (2) reported engagement in unsafe transactional sex (defined as a sex act in exchange for pay) in the past 30 days; and (3) reported engagement in one or more episodes of unprotected sex in the past 30 days. Study sites were randomly assigned to three treatment conditions: (1) Control arm receiving HIVRR sessions focused on equipping participating women with the skills to reduce the spread of HIV; (2) Treatment arm 1 receiving HIVRR sessions combined with a matched savings account (S) and financial literacy (FL) training with integrated behavioural economics principles (HIVRR + S+FL), aimed at training participants on issues related to the importance of savings, banking services, budgeting, and debt management; and (3) Treatment arm 2 receiving HIVRR, a matched savings account, financial literacy training, and vocational skills training and mentorship sessions (V), aimed at economically empowering women for purposes of starting up an income-generating activity (HIVRR + S+FL + V). The specific aims of the study are:

1. To examine the impact of a financial savings-led microfinance intervention using HIVRR + S + FL and HIVRR + S+FL + V on HIV biological and behavioural outcomes in WESW using RCT.
2. To examine intervention mediation and effect modification.
3. To qualitatively and quantitatively examine implementation in each study condition.
4. To assess the cost and cost-effectiveness of the HIVRR + S+FL and HIVRR + S+FL + V intervention compared to traditional HIVRR.

Assessments will be completed at baseline (pretest), 6, 12, 18 and 24-months post-intervention initiation. This study utilises an embedded experimental mixed methods design where qualitative data are also collected post-intervention across all three arms to explore participant experiences with the respective interventions, as well as key multi-level factors (i.e. individual, economic, family, contextual and programmatic factors) influencing participation.

As of writing of this paper (September 2020), the research team enrolled 542 WESW from 19 sites into the study. All participants completed baseline assessments and were tested for HIV and STIs. Participants from 18 sites received all four sessions of HIVRR and participants from 8 sites enrolled in the treatment conditions received all four sessions of FL. In addition, 237 savings

accounts were opened for women from 12 sites in the treatment conditions, and 17 participants who received the HIVRR and FL interventions completed qualitative interviews at 6-months post-intervention completion. Data collection is still ongoing.

Given the significant challenges associated with conducting research among WESW (Reed et al., 2014; Shaver, 2005; Sinha, 2017), and the high level of vulnerability of this population, especially due to criminalisation of sex work, mistrust, and their high mobility (Arnott & Crago, 2009; Goldenberg et al., 2016; Remple et al., 2007), the implementation of the Kyaterekera Project relies strongly on community stakeholders. More specifically, we continuously engage community stakeholders –as described below, to ensure proper adaptation of the study materials and compliance with best practices for conducting the study, including participant recruitment, maintaining participants' safety, intervention delivery, increasing response and retention rates, as well as to identify available community resources that may be available to our participants within the study region.

4.1. Collaborative process with key community stakeholders

4.1.1. Identification of stakeholders

Successful stakeholder engagement requires a broad, inclusive, and multifaceted understanding of the context in which the research study is conducted (Concannon et al., 2012). It begins with an inclusive perspective for identification of potential stakeholders, taking into account their interests, priorities, perspectives, and cultural aspects, including the study population to be recruited, considering those who are affected by the study in the local area, consulting with already known stakeholders, and building on that expertise to develop a richer understanding of potential and known stakeholders (Concannon et al., 2012). Based on these guidelines, the research team identified key community stakeholders who engage with WESW at different levels, for a variety of reasons, in addition to WESW themselves. More specifically, the following stakeholders were included in the process: WESW representing study participants from each of the seven districts in the study region; community-based organizations (CBOs) and non-governmental organizations (NGOs) working with WESW in the study region; community health workers (CHWs); financial institutions; research-based organisations; and government entities, including the Ministry of Health (District Health Officers – DHOs), law enforcement (District Police Commanders – DPCs), and local government officials, such as Chief Administrative Officers (CAOs), District Chairpersons (LCVs), and Office of the Mayor. All stakeholder representatives were invited to the initial meeting described below.

4.1.2. Initial meeting with community stakeholders

The first stakeholders' meeting was convened in February 2019 to introduce the Kyaterekera project to community stakeholders and potential collaborators; seek feedback on the potential of conducting the study in the region; and gauge interest from stakeholders and potential collaborators. The meeting was attended by all stakeholders, including CAOs, DHOs, LCV Chairpersons, DPCs, the Mayor of Masaka municipality –where our International Center for Child Health and Development (ICHAD)'s field offices are located, WESW from each of the seven districts, officials from CSOs and NGOs working with WESW in the region, including The AIDS Support Organization (TASO) Masaka, Reach the Youth (RTY) Uganda –our implementing partner, Rakai Health Science Program (RHSP), Blessing Basket (Ten by Three), Kitovu Mobile, Masaka Catholic Diocese, the Women's Organization Network for Human Rights Advocacy (WONETHA), and ICHAD's Uganda and US-based research teams. During this meeting, the researchers introduced the study, including the overall goal, study design and implementation, benefits to participants and communities, and overall study progress. Three panels focused on current issues, experiences, and lessons learned from working with WESW in Uganda and in other parts of the world were conducted. Stakeholders shared their roles in the region, experiences working with WESW, and opportunities and challenges, as well as recommendations for study implementation. Follow-up meetings

to update stakeholders on project progress were scheduled to take place annually throughout the study period.

As part of stakeholders' meeting (described above), the concept of a community collaborative board (CCB) was introduced to allow interested individuals make an informed decision on whether to serve on the CCB –if invited, to further guide the research team on the implementation of the study. More specifically, this part of the meeting aimed at introducing the concept of CCB, discussing the roles and responsibilities, composition and management of the board, as well as expected benefits to both the research team and study participants. Following the meeting, 12 individuals volunteered to serve on the Kyaterekera CCB for the study period of five years. Below, we detail the contributions of community stakeholders at the various stages of study implementation.

4.1.3. Role of stakeholders in the implementation of the Kyaterekera Project

Site identification and assessment. The Kyaterekera project is being conducted in 7 districts of Masaka, Lwengo, Kyotera, Rakai, Mpigi, Kalungu and Lyantonde, located in the southern region of Uganda. The overall HIV prevalence rates in this region are higher than the national average of 5.8%, ranging between 8.7% and 11.3% (UAC, 2020), with prevalence among WESW in Rakai and Masaka districts alone as high as 61% (Ssembatya et al., 2015). To identify and assess potential study sites (HIV hotspots), we engaged stakeholders currently working with WESW (RTY, RHSP and TASO), who provided us with contact information of women leaders/representatives, also known as 'gatekeepers,' who manage WESW (including managers, brothel owners, pimps, lodge owners) (Hong et al., 2014), hereafter referred to as *Site coordinators*, at each potential site. The potential sites included towns, HIV hotspots along major boarder highways, fishing villages, and landing sites along Lake Victoria –major places where WESW seek economic opportunities, but also have HIV prevalence rates of 22% and higher (Morris & Ferguson, 2006; Seeley et al., 2009). Site coordinators provided us with insights on the potential ways of engaging with WESW, the health services available to them, including ongoing research programmes and interventions, and the appropriate locations to meet with potential participants.

The site assessment exercise took place between November and December 2018, and involved capturing the following data: (1) district details, including name, subcounty, nearest government health facility, and distance to the facility; (2) primary/major economic activity at the site, name of nearest bank/financial institution, and distance from the site to the bank; (3) site details, including name, site coordinator details, duration of the coordinator at the site, estimated number of WESW at the site, average age of WESW, WESW peak/off peak seasons, geographic coordinates, and location (rural vs. urban setting). At the end of the exercise, the team identified and assessed 84 HIV hotspots/ sites, with an estimated 2100 WESW. Sites were later evaluated based on proximity to each other, accessibility, number of WESW, and location, resulting in 33 sites that were later randomised to the three study conditions.

Formation of the community collaborative board (CCB) quarterly meetings. At the heart of any study engaging stakeholders is the CCB– a group of local experts who together help the research team to make decisions that best direct how the project is conducted (Pinto et al., 2011; Wechsberg et al., 2015). It is a collaboration of researchers and community stakeholders to ensure that the best possible project is implemented with the support of the community. CCBs are critical to providing perspectives to translate methodological designs into real life settings (Pinto et al., 2011), such as helping with participant recruitment, and ensuring best practices for engaging with study participants.

Following the initial meeting with stakeholders, 12 individuals representing various stakeholder groups volunteered to serve on the CCB. These include: seven WESW representing each district in the study area, one DPC, one DHO, one representative from TASO, one representative from RTY, and one representative from RHSP. The members agreed on the following terms: (1) each participating district to have an opportunity to host a CCB meeting, (2) meetings to be held on quarterly

basis, (3) host district to be decided by CCB members at the quarterly meeting, (4) meeting agenda to be suggested by the research team, (5) principal investigators to attend all CCB meetings –if available, (6) meeting minutes be shared in time before the next meeting, and (7) CCB members to sign commitment/letter of agreement. CCB meetings were held in May 2019, October 2019, and virtually in June 2020, to update the members on study progress, and discuss best practices to support the implementation process. The following recommendations from the CCB meetings have been incorporated into the study protocol as follows:

1. *Considerations for recruiting study participants.* CCB members recommended that the research team utilise site coordinators instead of using flyers to recruit WESW. This was intended to reduce stigma associated with sex work that may prevent eligible women from turning up for screening; and prevent non-WESW from showing up and benefiting from incentives. Moreover, given that site coordinators know the women in their networks, they could reach out to them directly, including those who do not identify as WESW, but do engage in sex work. An amendment was submitted and approved by IRB.
2. *Handling WESW who do not meet the inclusion criteria.* CCB members recommended that prior to the screening process, the research team should let the women know that the selection process was by chance and that some women would be selected, and others not. Those who do not get selected may be able to participate in future opportunities. This was intended to avoid conflicts between women who get selected and those who do not at the same site.
3. *Participants' verification process.* The research team had proposed to use birth certificates and recent medical forms to verify both age and nationality as part of the screening process– as with our previous and ongoing studies in the region among adolescents. During the CCB meeting, however, members recommended using national identity cards and/or passports, as these documents were less likely to be forged compared to medical forms and birth certificates.
4. *Appropriate time and location to meet with WESW.* The research team had assumed that it would be appropriate to meet with WESW during evening hours when they arrive for work. However, following the CCB meeting, it was recommended that meetings be scheduled in mid-morning, when women are not busy with customers (off-pick). The meeting locations recommended by site coordinators included lodges/brothels and health centres.
5. *Gender matching.* Based on previous experience from our other studies in the region, the research team had proposed to use female research assistants to engage with the women during screening, data collection, and intervention delivery. However, following the CCB meeting, women representatives indicated that they were comfortable with both male and female research assistants. An amendment was submitted and approved by IRB.
6. *Addressing challenges associated with engaging participants in intervention-related activities.* During study implementation, the research team observed that the attendance rates for HIVRR sessions were lower compared to FL sessions. A number of women ($n = 126$) who had tested HIV negative declined pre-exposure prophylaxis (PrEP) enrolment for fear of being identified as HIV positive, due to similar packaging to ART medication, and inability to adhere to daily medication. Some women were unable to obtain their national identification cards to facilitate savings account opening. To increase attendance, CCB members recommended the research team to work with site coordinators to mobilise WESW to attend sessions. This included making phone calls to participants and reminding them of the day and time for each session. For PrEP enrolment, women representatives volunteered to personally meet with WESW in their respective districts to try to encourage them to enrol, in addition to the research team's efforts. Indeed, some women ended up enrolling during HIVRR sessions, as well as during the 6-month follow-up assessments. Regarding packaging of PrEP, TASO –one of our implementation partners, initiated efforts to repackage the pills in regular medication bottles. Finally, to support WESW in obtaining their national identification cards, CCB members suggested continuing to call and remind the women to pick up their cards and provide

facilitation to pick-up centres. Indeed, the research team followed up with all WESW via telephone to offer information for card pick-up and provided facilitation in the form of transportation to those who were unable to travel to distant places to pick up their cards.

Development of data collection and intervention protocols. Because WESW's literacy and knowledge of scientific methods and concepts often differ from those of researchers designing trials, it is critical to develop study tools and protocols that are culturally appropriate, effective, and relevant to participants (Mikesell et al., 2013). Community stakeholders play an important role in the development of trial tools, including study measures, educational and training materials, such as curriculum and handbooks (UNAIDS, 2011). Engaging stakeholders in this process provides insights into issues that influence study participation, engagement, and retention, as well as sustainability of research outcomes (Woodsong et al., 2014).

For this study, data collection tools and intervention manuals (HIVRR curriculum and FL manual) were adapted from existing materials utilised in our prior HIV studies implemented in the region (Ssewamala et al., 2008, 2018; Tozan et al., 2019), and from prior studies conducted among WESW (Mergenova et al., 2019; Tsai et al., 2011; Witte et al., 2015). We supplemented these documents with information and literature available from the Uganda Ministry of Health, as well as from our collaborators working with WESW in the study region.

Stakeholder engagement focused on adaptation and alignment of study materials to fit the cultural context, best practices for engaging and working with WESW, alignment with community resources, as well as policy guidelines. Specifically, the development and adaptation process involved forming two working groups consisting of the research team –US and Uganda-based teams, and two CCB members representing WESW. Once the Uganda team made changes to culturally adapt the materials, the two CCB members reviewed all documents and helped to infuse appropriate language, examples, activities, and experiences relevant to WESW. In particular, they revised the manuals to include the language of sex work, such as commonly used language/words, types of relations, the 'Kyaterekera Café menu' that provides strategies to reduce high risk-taking behaviours, specifically, those related to unprotected sex. The HIVRR curriculum was finalised with four sessions. The six session-FL manual was also adapted and approved by these two representatives of CCB. All study-related materials and protocols were translated into Luganda – the local language widely spoken in the study region.

Participants' screening, recruitment and enrolment. As previously stated, site coordinators identified locations/venues to facilitate participant screening, recruitment, and data collection. These were private venues where WESW felt comfortable engaging with the research team. Based on recommendations from the CCB, we utilised respondent-driven sampling and snowball sampling – recruitment approaches recommended for hard-to-reach populations, including WESW (Uusküla et al., 2010; Wayal et al., 2008). Specifically, site coordinators were our first point of entry, and they helped mobilise other WESW in their networks to come to the recruitment venues. Between June 2019 and March 2020, a total of 890 women from 19 sites were screened for eligibility; of these, 542 met the inclusion criteria, provided informed consent, and were enrolled into the study.

Data collection procedures. A summary of the data collection process is provided in [Figure 1](#). Data are collected via self-reports, biomarkers, and in-depth interviews (post-intervention completion). As the study involves collection and testing of biomarkers (HIV and STIs) at each of the five data collection points, we partnered with RHSP health clinic, a research-based institution that has been conducting HIV-related research in the region since 1987. The institution has also collaborated with the research team on previous and ongoing NIH-funded studies implemented in the study region. Given that RHSP also conducts research among WESW, this partnership was critical not

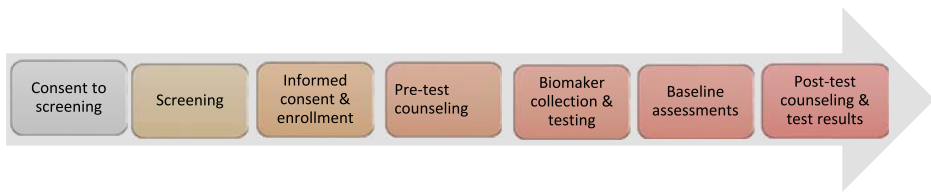


Figure 1. Kyaterekera study data collection process.

only to avoid duplication of services and double dipping, but also to leverage existing community infrastructure and resources to implement the study.

Following the Uganda National Policy Guidelines on HIV Counselling and Testing (Uganda Ministry of Health, 2005), all WESW who provide consent to participate in the study and to be tested have to undergo pre-testing counselling to prepare them for the test, and to make appropriate risk-reduction plans. Counselling is provided by trained and experienced counsellors from our community collaborating partners (TASO and Kitovu Mobile) that provide HIV services, including prevention, counselling and treatment services for HIV in the region. Blood draw for HIV and vaginal swabs for STI rapid testing (Gonorrhoea, Chlamydia and Trichomonas) are conducted by registered nurses under the supervision of RHSP. All samples are transported to RHSP laboratory for further testing and analysis. Following blood draw, participants proceed to complete baseline self-reported interviewer-administered assessments, conducted by trained ICHAD research staff. The interview lasts approximately 90 min. Following the interview, participants receive post-test counselling (from the same counsellor who conducted pre-testing counselling), and the test results are provided. Study-enrolled WESW who test positive for STIs receive treatment onsite; those who test HIV negative are initiated or linked to PrEP services provided by RHSP and TASO; and those who test HIV positive and are not on treatment already, are enrolled on ART and linked to long-term care at a health clinic of their choice. Follow-up is conducted after 30 days to make sure that participants are still enrolled in care.

In addition, these collaborating agencies provide a range of HIV prevention, treatment and care services, such as testing, condom distribution, PrEP and PEP services, ART treatment, counselling services for individuals and their families, lobbying and advocacy, leadership training, and human rights awareness efforts. All these services are provided to our study participants directly as part of usual care, or on a referral basis. Representatives from these organisations work with us to provide specialised training (e.g. on PrEP) during HIVRR sessions delivered by CHWs. Moreover, during the Covid-19 pandemic, these organisations have been working with site coordinators to refill ART and PrEP for WESW, as well as personal protective items, including gloves and hand sanitizers, to reduce the risk of infection.

Working with community stakeholders to deliver HIV risk reduction intervention. The Kyaterekera project implements four intervention components: HIVRR sessions, a matched savings account, financial literacy training, and vocational skills training and mentorship, all of which are implemented by our community collaborators that are experts in the corresponding areas. At each study site, the 2-hour HIVRR sessions are delivered twice a week by trained CHWs who have worked with ICHAD on other studies in the region, under the supervision of ICHAD staff. WESW participating in the study complete pre and post HIVRR surveys, and CHWs complete fidelity assessments for quality control at the end of each session. During session three, personnel from our collaborating partners (TASO and RHSP) are invited to give a tailored presentation on PrEP. As part of this session, WESW have the option to enrol on PrEP (if they did not do so during recruitment), and refills are provided as needed.

Financial literacy training sessions are delivered once a week by trained ICHAD staff. Sessions focus on bank services, saving, budgeting, and debt management. In addition, the financial economic empowerment component requires study participants enrolled in the treatment conditions to open up savings accounts in financial institutions regulated by the Central Bank (Bank of Uganda). For this purpose, we partnered with two recognised banks in the study region (Equity bank and Stanbic bank) that have an ongoing working relationship with the research team through previous or current studies with similar components. Specific to the study, financial institutions agreed to: (1) meet with study participants during FL sessions to provide an overview of bank services, explain how participants can assess their services i.e. requirements to open an account, and the different services and products they offer; (2) open savings accounts for all participants at their respective sites, instead of going to the banks; (3) be available to answer participants' questions over telephone or in-person throughout the intervention period; (4) designate a contact person at the bank to help WESW while making transactions; (5) provide monthly bank statements to participants free of charge; and (6) provide savings account with no monthly maintenance charges.

Vocational skills training sessions are conducted by RTY, our implementing partner. The team provides an overview of the programme, roles and responsibilities, and administers the Training Needs Assessment (TNA) to ascertain participants' specific vocational training needs. The team then identifies and assesses vocational training schools in the study region that are registered under the Uganda Ministry of Education Business Technical Vocational Education and Training (BTVET), to provide specialised training to WESW based on their training needs. These training institutions signed a memorandum of understanding with the research team. Following the training, women are linked to mentors in the community to obtain hands-on training through an apprentice-like programme.

Formation of the Data and Safety Monitoring Board (DSMB). The Data and Safety Monitoring Board (DSMB) is an independent group of experts charged with reviewing study data for data integrity, participant safety, study conduct and progress, and providing directives regarding study continuations, modifications, and terminations (NIMH, 2015). While recommended or required for many NIH-funded clinical trials, membership should ideally include local community members. The research team identified six individuals with contextual knowledge and expertise in public health, medicine, social work, and HIV research in Uganda to serve on the Kyaterekera DSMB. Four members agreed to serve on the board: two members are affiliated with academic institutions (Makerere University and Kyambogo University), one member is affiliated with Mildmay Uganda, a Pediatric Palliative Care Training and Clinical Centre of Excellence for provision of comprehensive HIV & AIDS prevention, care, treatment and training services; and the other member is affiliated to a health institution in the study area. The first DSMB meeting was convened in November 2019. The goal of the meeting was to introduce the study to board members, provide study progress, discuss member roles and responsibilities (provided above), and provide recommendations for data management and safety.

Support from government institutions. We consider it critical to engage government institutions if we are to utilise study findings to contribute to research-informed policies in Uganda. Relevant to this study, the AIDS Control Program – a division under the Uganda Ministry of Health (MOH) is responsible for the development and implementation of policy and technical guidelines for HIV/AIDS control and prevention. This division focuses on the health sector response to HIV epidemic, including reducing transmission and increasing access to care, treatment and support, all of which directly impact our study participants. District chairpersons, who represent the government at the district level, oversee the district health sector (headed by DHOs) charged with the implementation of HIV/AIDS related programmes and policies. As such, it was necessary to obtain their support and approval earlier on, but also to engage them throughout study implementation. Moreover, the DHOs provided us with referral resources, including contact information in each district in

the study region, to facilitate referrals for women related to HIV treatment and care, PrEP, and also with resources on domestic violence and mental health services, among others. In addition, the Uganda Joint Medical Store – a private not-for-profit organisation working with the Ministry of Health and charged with receiving, management, and distribution of medicine and health care supplies, including HIV medication and laboratory equipment, donated nearly one million condoms to our study participants. These condoms are being distributed during assessments and intervention delivery.

Finally, given the criminalisation of sex work in Uganda, working with law enforcement (Uganda police/DPCs) is essential to ensure the safety of study participants during all study-related activities, as well as the safety of our research team. During the initial stakeholders' meeting, our team created a safe environment where law enforcement and WESW engaged in a dialogue, which enabled WESW to freely express their views without fear of being arrested. Moreover, as part of the CCB, all members including the DPC received sensitivity training focused on working with WESW – highlighting their human rights, rights to health care, as well as how to work effectively with the police to address challenges. As such, the research team has been able to convene large meetings without interference from law enforcement.

5. Training of the selected stakeholders

Education and training are critical components to stakeholder engagement that are necessary not only to provide information about the study, but also build capacity and ensure sustainability of research outcomes (Goodman & Sanders Thompson, 2017). CCB members and CHWs received sensitivity training focused on issues related to working with WESW, including the myths and facts about sex work, drug use, the impact of stigma on women's access to health services, laws that protect women's rights to health care, and accessibility of services by WESW in communities. In addition, we conducted the Training of Trainers (TOT) through which CCB members, including WESW representatives, were trained on how to deliver HIVRR sessions. The training aimed at providing an overview of the 4 HIVRR sessions, reviewing the session content, practicing how to conduct session activities via role plays, and building self-efficacy and motivation within trainees as they conduct the sessions. The same individuals were trained on how to deliver FL sessions. The research team continues to offer refresher courses throughout the study period.

6. Discussion

In this paper, we describe the process by which the research team engaged in a collaborative process with key community stakeholders to implement the Kyaterekera project, among WESW in southern Uganda. We detail several engagement strategies utilised by the research team, including an intensive collaborative process and training of key players to implement the study and several examples of the ways in which this process has shaped the final study protocols.

Previous studies have documented that intensive stakeholder engagement increases a sense of community ownership and improves the potential for acceptability, efficacy, as well as cultural and contextual sensitivity (Baptiste et al., 2007; Kelly et al., 2000; McKay & Paikoff, 2007). Moreover, given that most HIV-related interventions are developed outside of SSA, involving stakeholders in the adaptation process is critical (Goldenberg et al., 2015; Kagee et al., 2020; Reed et al., 2014; Sinha, 2017). To this end, our research team has engaged several key community stakeholders, including WESW themselves, CBOs and NGOs working directly with WESW in the study region, CHWs, financial institutions, research-based organisations, and government entities. Each of these stakeholders has played a critical role in the adaptation and implementation of the study.

In addition, our study illustrates the level of time and effort that community engagement requires (McKay et al., 2020). Implementation of the study has leveraged existing infrastructure,

relationships, and partnerships that the research team has built in the region over the years. Specifically, ICHAD –under the leadership of the Principal Investigator, has been working in the greater Masaka region of Uganda for more than fifteen years. Over this time, the centre has developed long-lasting relationships with local leaders, CBOs, NGOs, research-based organisations, schools, religious leaders, health clinics, and policymakers. In addition, ICHAD has established field offices in the region, housing multiple studies funded by the National Institutes of Health. Therefore, researchers should be prepared and willing to invest time and resources in building sustainable partnerships to engage stakeholders and to sustain partnerships through a full range of collaborative activities (McKay et al., 2020).

It is important to note that maintaining long-lasting community relationships and partnerships takes time and requires trust, transparent communication, ongoing engagement and exchange of information, as well as efforts to ensure community capacity building (Dave et al., 2018; Wilkins, 2018). Over the years, ICHAD has engaged in a mutually beneficial relationship with the Masaka Catholic Diocese that has deep ties with local leaders, health and educational institutions, NGOs, and communities in the study region. Through this relationship, the centre has leveraged the Diocese's well-established organisational structure, contacts and networks, community trust and cultural integrity, as well as their ability to identify mutual community benefits (Ssewamala & Ismayilova, 2008). All these aspects have been instrumental in the implementation of previous and ongoing studies, as well as the engagement of new stakeholders and partnerships. As part of community capacity building, the centre has recruited and trained individuals born in the study region, to serve in various capacities, including as research assistants, data collectors, peer mentors, intervention facilitators and project coordinators. Moreover, to sustain these relationships, the research team continue to engage all stakeholders on a regular basis on new and ongoing projects, future opportunities, as well as in the dissemination of research findings during the centre's annual conferences organised in the study region.

Further, engagement with the CCB has provided the research team with an opportunity to implement the best practices for working with WESW, taking into consideration their specific needs while also ensuring their safety. Peers enable entry into the target population and give voice to their fears and concerns (Rennie & Sugarman, 2010). In our study, working with site coordinators facilitated community entry and ensured appropriate ways to successfully recruit WESW into the study. Moreover, engaging CCB members has helped the research team to timely address emerging issues related to participants' attendance and retention in intervention sessions, as well as issues around PrEP initiation with implications for HIV-related practice and programming.

Increasing the likelihood for effective HIV control and other public health interventions among hard-to-reach populations, such as WESW, requires regular monitoring (e.g. incidence or prevalence of HIV and STIs, and estimates of viral load suppression) among those living with HIV (Hladik et al., 2017). Our study aligns with this recommendation. Specifically, biomarker testing is conducted at all time points to identify new HIV and STI infections and facilitate timely referral to treatment services.

Finally, our experiences and processes are within a context of a having a long-standing partnership (15+ years) in the community. However, even with this long-standing relationship, we acknowledge that working with WESW was a new population for us. Previously, our team had primarily worked with children, adolescents and families impacted by HIV in the study region. As such, we had to make extra arrangements, including conducting sensitivity trainings to prepare ourselves, our field team and existing stakeholders on working with this new population. By leveraging our existing relationships, we had to identify and engage new stakeholders, as well as build new trust among WESW and their communities. Moreover, we had to work with a CCB and DSMB for the first time, to adapt and implement our study. As such, it may be important for new investigators with fewer years of experience to discuss long-term goals with new community partners, and the potential for establishing long-term initiatives.

Taken together, this paper highlights the role of engaging community stakeholders to increase a sense of community ownership, improve acceptability of research studies, as well as considerations for maintaining stakeholder relationships. In addition, we acknowledge the level of time and effort to be committed to stakeholder engagement, highlight considerations for implementing best practices for engaging hard-to-reach populations, and increasing the likelihood of effective programming for populations at a higher risk of HIV. The process described may have important implications for future research among hard-to-reach populations, especially in low-resource settings.

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Disclosure statement

No potential conflict of interest was reported by the author(s).

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