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LESSONS LEARNED FROM THE IMPLEMENTATION OF HIV BIOLOGICAL-BEHAVIORAL SURVEYS OF KEY POPULATIONS IN THE CARIBBEAN

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Abstract

In the Caribbean region, HIV prevalence is high among key population (KP) groups, such as sex workers and men who have sex with men. However, there is a lack of high-quality, population-level data estimating HIV prevalence and population sizes of KPs. The President's Emergency Plan for AIDS Relief has funded and completed five bio-behavioral surveillance (BBS) surveys using respondent-driven sampling methodology to target KP in the English-speaking Caribbean region. We describe the experience of implementing bio-behavioral surveys in the Caribbean region and document the context, processes, successes, and challenges, and make recommendations for future survey implementation. Successes include the provision of estimates of nationally representative HIV data and KP size estimates to improve HIV programming and provision of tools for routinization of BBS. Challenges include small KP sizes, the legal context, and the cost and speed of implementation. Future bio-behavioral surveys should include well-planned formative assessments and stakeholder involvement.

SUMMARY

BBS surveys for KP using RDS in the Caribbean region have provided MOHs with high-quality HIV prevalence data, denominators for the HIV continuum of care, and estimations of GAM indicators to improve KP programming in the region. BBS implementation in the region has built institutional capacity of MOHs, providing tools and training to MOHs, along with the ability to conduct further rounds of BBS to monitor the epidemic and HIV service needs among KP. Our

experiences with BBS have demonstrated the ability to facilitate the diagnosis of HIV and other STI and linkage to care, with the ultimate aim of accessing treatment and prevention of new infections among KP in the region.

Keywords

respondent-driven sampling; sentinel surveillance; GAM; global AIDS monitoring; behavioral surveillance

BACKGROUND

THE IMPORTANCE OF QUALITY HIV DATA

Meeting the UNAIDS *95-95-95* targets (United Nations Program on HIV/AIDS [UNAIDS], 2014a) to improve HIV prevention, care, treatment, and end the AIDS epidemic by 2030 requires national- and subnational-level data. These data include the number of people at risk of acquiring HIV and the number of people living with HIV (PLHIV) in the population of interest at the desired geographical level. These data are denominators for the HIV clinical continuum of care, but are difficult to accurately obtain, especially among key populations (KP) such as men who have sex with men (MSM) or sex workers (SWs). In many geographic regions globally these populations have an HIV prevalence several times greater than that of the general population (De Boni, Veloso, & Grinsztejn, 2014). Stigma, discrimination, and local laws may lead to distrust of public institutions, making accurate population size and prevalence estimation difficult. Quality data generated by routine care and treatment programs are sometimes limited in scope and may not represent the entire population of PLHIV. In contrast, biological-behavioral surveys (BBS) provide population-level estimates of the number of PLHIV, HIV prevalence, and estimates of population-wide intervention coverage, including viral load suppression levels when adequate sample sizes can be obtained (Hladik, Banech, Bateganya, & Hakim, 2016). By characterizing the epidemic, these data inform HIV prevention and control strategies.

CARIBBEAN CONTEXT AND DATA GAPS

HIV prevalence in the Caribbean is estimated to be 1.1% (UNAIDS, 2014b). The epidemic is mixed—generalized but also concentrated among KP. Prevalence among KP varies by country, but is consistently much higher than in the general population (1.3% among the general population, 19.0% among MSM, and 16.6% among FSW in Guyana; 1.7% among the general population, 32.8% among MSM, and 4.1% among FSW in Jamaica; UNAIDS, 2013, 2017). Given this disparity, addressing HIV among KP is a critical strategy to control the epidemic. Institutional factors, including stigma (Stangl, Lloyd, Brady, Holland, & Baral, 2013), laws, and social policy (Beyrer et al., 2012; Shannon, Strathdee, et al., 2015; Smit et al., 2012), disenfranchise MSM and SWs, and may lead to data gaps that ultimately threaten the region's progress toward the UNAIDS targets.

ROLE OF BBS IN KP HIV EPIDEMIOLOGY AND PREVIOUS SURVEYS

There are limitations to estimating HIV prevalence and population size among KP, both for programmatic data collection and for BBS. For BBS, surveys are costly with long timeframes. For routine data, barriers to disclosure of KP status and HIV risk behaviors affect data collection (Underhill et al., 2015). Lack of high-quality electronic HIV surveillance systems and nonstandardized data collection among facilities also hinder routine data collection. In these data-limited contexts, surveys that generate population-level HIV estimates increase the understanding of HIV epidemics and their dynamics among KP. When robust sampling approaches such as time location sampling (TLS) or respondent driven sampling (RDS) are used, data from these surveys are preferable to programmatic data due to their ability to produce a random sample of the desired population after mathematical adjustment. BBS provide high-quality estimates through RDS and TLS sampling methodologies and the resulting data fill gaps in HIV epidemiology. BBS samples are sized for national or subnational population-level estimates of the number of KP and HIV/STI prevalence as determined by biological testing. They also estimate the prevalence of sexual risk behaviors, health care utilization, and stigma and discrimination, among other measures, to inform HIV/STI and KP programming.

Due to resource requirements, complex methodologies, and need for relatively large samples of participants from hidden populations, there has been limited utilization of BBS with representative sampling methodology in the Caribbean region. However, a number of HIV prevalence surveys have been undertaken in the Caribbean region, both in the general population and among KP. A limitation of most of these surveys is the lack of a sampling methodology that provides population-level data (Montealegre, Johnston, Murrill, & Monterroso, 2013). Of published results from HIV prevalence surveys, one employing a convenience sampling methodology in Trinidad and Tobago found 40% HIV prevalence among MSM (Bartholomew et al., 1987), while similar studies in Jamaica found a prevalence of 31.4% in MSM (Duncan et al., 2010) and 9% among SWs (Duncan et al., 2010). KP HIV prevalence studies from the Dominican Republic in 2004 and 2008 using RDS found HIV prevalence of 10.7% and 4.8% among MSM and SWs, respectively, but the results were not published in peer-reviewed journals (Centro de Estudios Sociales y Demográficos & Macro International Inc., 2008). These results demonstrate that HIV prevalence among KP is high in these countries. However, the majority of the epidemics among KP have not been characterized using representative methodology, and the lack of these data reveal a gap in the region that limits reaching goals for HIV control.

A PEPFAR REGIONAL EFFORT: BBS

Since 2010, the President's Emergency Plan for AIDS Relief (PEPFAR), has supported a series of BBS for KP in the English-speaking Caribbean. These surveys are implemented by ministries of health (MOHs) and nongovernmental partners through cooperative agreements. This article outlines the processes, successes, and challenges of conducting these surveys, and makes recommendations for improving their implementation and utility. It also provides recommendations for using alternate methodologies when surveys may not be relevant, necessary, or cost-effective.

METHODOLOGY FOR IMPLEMENTATION OF BBS IN THE CARIBBEAN

In 2010, PEPFAR approved a series of BBS for the Caribbean to characterize the HIV epidemic among KP. Our implementation proceeds according to these steps: We secure funding for surveys by an annual regional operational planning process, whereby PEPFAR approves the proposed activities. During this process, we engage host-country MOHs in developing country-specific work plans, seeking concurrence for the activities prior to final PEPFAR approval of the regional plan. National HIV/ AIDS programs within MOHs serve as the primary implementer of the survey, and funding is provided by a U.S. government cooperative agreement mechanism, along with direct technical assistance and collaboration provided by U.S. government agency-specific subject matter experts. The MOH hires survey staff with the aim of strengthening in-country capacity to conduct similar surveys. We also provide funding to external technical assistance providers, often universities or nongovernmental organizations (NGOs), to supervise the development of protocols and operationalize the studies as an implementing partner.

We apply for approval from agency-level and relevant partner ethical review boards, after which we initiate survey planning with MOHs and the technical implementing partner by in-country site visits. During this phase, we finalize budgets, determine logistical requirements, hire survey staff, and establish relationships with community stakeholders. Given social and political sensitivities surrounding KP, a successful survey hinges on community buy-in. We establish a steering committee with representatives from the population to guide the team.

The first phase of survey implementation is the completion of a formative assessment (FA), for which the primary goal is to determine the most feasible sampling methodology for the selected population, TLS (MacKellar, Valleroy, Karon, Lemp, & Janssen, 1996) or RDS (Heckathorn, 1997). Our criteria for selecting a survey methodology include the willingness of population members to be sampled at public venues, the strength and connectedness of social networks, and the willingness of members of the population to recruit others into the survey. Other goals of the FA are to characterize the population, begin to define the public health- and HIV-related needs of the population, and foster community support for the survey among the population by soliciting their input and partnership.

Our FA methodology consists of several activities, the first of which is to conduct key informant interviews, in-depth interviews, and focus group discussions. Key informant interviews gather information from crucial individuals and organizations working with KP. In-depth interviews are similar, but they gather information from self-identified members of the KP community. Focus group discussions collect information from diverse members of the KP community through group conversations. Other activities include mapping of KP venues, which characterizes the population's social geography. Next, we observe and enumerate KP venues. This activity validates venues as KP locations and provides an estimation of the KP that frequent a defined geographic area. We validate and analyze data collected from these activities and develop a final report with recommendations for the methodology.

Once the results from the FA have been disseminated to stakeholders and approved by the MOH, we begin formal survey activities. Table 1 outlines the steps we take during the BBS. The main component of BBS is to administer a biological and behavioral survey within the population of interest. Secondary objectives of BBS are listed in Table 1. The expectation is that the BBS are sustainable and that a baseline can be established for repeat implementation by the MOH to collect longitudinal data such as HIV incidence and behavioral trends among KP.

All of the PEPFAR-funded BBS FAs in the English-speaking Caribbean region have recommended the RDS methodology, and the experiences described herein are specific to this methodology. At secure survey sites, we screen and provide informed consent to participants, after which we administer a standardized questionnaire (Table 1). Questionnaire domains are designed to collect indicator data in relevant epidemiological, program, and policy areas (Table 1). The questionnaire content has evolved over time, originating from standardized indicators published in the Centers for Disease Control and Prevention's guidance, entitled: "Biobehavioral Survey Guidelines for Populations at Risk for HIV" (World Health Organization, 2017). The questionnaire content is then modified for the local context throughout each new round of implementation in order to use past experience to inform and improve successive implementation. The changes to the questionnaire have been iterative and have coincided with the approval and local validation of biological testing technologies that are feasible within the survey context. When available, we collect viral load data and other continuum of care indicators to enable the generation of 95-95-95 KP cascade estimates and maximize the amount of usable data collected per dollar spent.

We compensate patients for travel, time spent answering the survey questions, and recruitment of other participants. We collect samples for a variety of tests (Table 1). We provide immediate results for rapid tests, and confirmatory results are provided during subsequent participant visits. We link participants to counseling and care if they are found to be newly HIV positive or if they are known to HIV positive but not in care. We maintain all participant anonymity permanently. Once data collection is complete, cleaning and analysis of the data begins. We weight collected data according to the sampling methodology used (Salganik, 2006). Finally, we produce a final report, which is vetted and approved by our agency and the respective MOH before we review the results in a final dissemination meeting with stakeholders to inform HIV programming for KP.

SUCCESSSES, LESSONS LEARNED, AND CHALLENGES

SUCCESS: IMPLEMENTATION

PEPFAR's Caribbean Regional Office has supported the completion of five BBS for KP in the region: three BBS among MSM (Barbados, Trinidad and Tobago, the Bahamas) and two among SW, in Antigua and Barbuda and Trinidad and Tobago. Table 2 lists our completed and ongoing surveys. All of the completed studies were preceded by an FA. Analyzing the FAs, we found RDS (versus TLS) to be the preferred sampling methodology in all cases. This is partly due to RDS's ability to reach hidden KP who might otherwise be missed in a venue-based survey and because many KP did not feel comfortable having blood drawn and answering sensitive questions in public settings. Operational and implementation challenges

have led to reversion to convenience or snowball sampling methodologies for other surveys implemented in the region. The BBS described here are among the first to successfully implement RDS methodology. In some cases, host governments have been hesitant to release the BBS results to the public due to fears of public perception and potential issues with stigma and discrimination of the KPs. As a result, study data have predominately been used for internal planning rather than public reporting. Estimates of HIV prevalence for two of the four completed studies are available in the UNAIDS global AIDS reporting (Ministry of Health, Government of Antigua and Barbuda, 2015; Ministry of Health, Government of Trinidad and Tobago, 2016).

SUCCESS: CLOSING DATA GAPS AND UNDERSTANDING HIV BURDEN AND PROGRAMMATIC NEEDS

Through these surveys, we have increased the availability of data and improved knowledge of the HIV epidemic in the region. These surveys have provided the first population-level estimates of HIV prevalence, HIV risk behaviors, and population size estimates among KP in each of the four countries. These surveys improve MOHs' ability to report UNAIDS Global AIDS Monitoring (GAM) indicators (Ministry of Health, Government of Antigua and Barbuda, 2015; Ministry of Health, Government of Trinidad and Tobago, 2016; UNAIDS, 2016), which contribute to international HIV reporting and understanding. The GAM KP indicators are metrics for monitoring regional progress toward the *95-95-95* targets (Pan American Health Organization, 2015) and provide baseline or comparison data for progress reports.

Population size estimates provide a denominator for the continuum of care for KP. Other indicators from the survey inform the continuum of care, such as a population-level estimate of the number of KP who are retained in HIV care services or who are virally suppressed (Hladik et al., 2016). These data provide details for scale up and coverage of interventions and are key to guiding budgeting and strategic planning. Furthermore, as collection of KP data disaggregates becomes integrated into routine health information systems, the clinical estimates can be refined by triangulation with data gathered from population-level data. For example, gaps in HIV prevention and treatment coverage for KP sub-populations that do not interact with the health system that are identified during BBS can inform interventions to try to reach those who do not seek care.

Results from the surveys can identify gaps in HIV prevention, care, and treatment programming. By assessing service uptake and preferred approaches for receiving routine and sexual health services, MOHs and community-based organizations (CBOs) have access to information to guide technical approaches and service delivery models for KP. Surveys have increased MOHs' capacity to implement similar projects to improve data collection. The surveys have been implemented with national AIDS program staff whose skills have been built by implementation of RDS methodology and RDS-weighted analyses. The BBS have improved the research and analytical abilities of MOHs to conduct further rounds of BBS in order to monitor the epidemiology of HIV among KP and their programmatic needs. During all BBS, MOH staff have aided in final BBS report preparation and dissemination of results to key stakeholders, including the wider MOH and KP-inclusive CBOs.

SUCCESS: ADDED VALUE

We conducted our BBS in partnership with KP and CBOs. This participatory approach is critical to ensure ongoing dialogue and community participation through-out the survey. These partnerships strengthen relationships between the MOH, CBOs, and KP, extending beyond the lifetime of the project. Fostering greater collaboration permits multisectoral stakeholder involvement in addressing KP community needs. For example, in one country, a steering committee was formed during the survey. That committee continued beyond the project, expanding to serve as a platform for technical planning and program implementation, based on the results of the survey. The committee also liaises with the MOH to review data from other sources and facilitates discussions about KP programming, ensuring a wide range of stakeholders contribute to the ongoing discussion about KP planning.

PEPFAR programming in the Caribbean region has been improved based on results from the BBS. With the availability of representative estimates for specific KP groups, analyses in one country revealed that HIV prevalence among MSM was much higher than in the general population, while FSW HIV prevalence in another country was lower than expected and close to the general population prevalence. This information permits an enhanced focus of resources on more vulnerable KP groups and potentially increased efficiencies in programming and funding allocation.

Ethical obligations require linkage to care for participants testing positive for HIV/STIs in the survey. This mandate serves as a vehicle to enhance access to services and bolster community confidence in HIV clinical services available in the public sector. Further, since these studies use peer recruitment and social networking to reach hidden populations, a proportion of those who test HIV positive are newly diagnosed. By diagnosing PLHIV and linking them to care, BBS facilitate referral to antiretroviral treatment and ultimately prevention of new infections among KP. Study-specific peer navigators have been hired and trained to provide linkage to care services in order to maintain anonymity for study participants.

LESSON LEARNED: INDISPENSABLE FAS

FAs are pivotal to the success of a BBS. During our formative work in Antigua and Barbuda (pop. < 100,000), MSM interviewed indicated an RDS survey of MSM would not be successful due to the lack of a socially networked community. However, SWs indicated a survey would be successful within their well-networked population of mostly migrant women. Indeed, to our knowledge, this was the first and only RDS BBS conducted in the Eastern Caribbean region that met its sample size targets, and it did so within four months of initiation. This may be attributed to the fact that SWs in Antigua and Barbuda are well connected. Another factor was that the SW outreach program was well established at the time of survey implementation. These are factors that were identified during the FA.

LESSON LEARNED: RISK FACTOR DATA COLLECTION

BBS offer enhanced collection of risk factor data compared to traditional routine surveillance or in clinical settings, which often do not collect information on KP status. Lack

of risk factor data, including classification of KP status, is particularly problematic in the Caribbean context, where highly concentrated epidemics among KP persist. Data collected by BBS inform KP-specific clinical continuums of care, programs for KP groups or subgroups that are disproportionately affected by HIV, and where service gaps exist for those groups.

CHALLENGES TO BBS

- In the Caribbean region, many national populations are less than 100,000 persons. Given that KP > 18 years old constitute only a fraction of the total population, reaching appropriate sample sizes in surveys can be difficult. This is especially true when survey participation is affected by high refusal rates or unwillingness to disclose KP status by stigmatized groups such as MSM. Sub-national surveys in other global regions could encounter similar difficulties.
- The decision-making process for setting levels of incentives for survey participation can be difficult. The appropriate amount might vary considerably by KP group. For example, the risk of negative consequences resulting from disclosure of KP status for SWs might be lower than for MSM. Therefore, some MSM might not be motivated to participate in a survey no matter how great the incentive. Mean-while, relatively high-valued incentives could be coercive to SWs, while small incentives might be sufficient to motivate groups of low socioeconomic status SWs. Ethical review boards may question incentives that appear to exert undue influence to an outsider. On the other hand, in one country, SWs revealed to the study team that proposed incentives were not high enough to entice many FSWs into the study, because they could earn more money per hour working.
- BBS are expensive compared to other types of surveys. Specifically trained technical staff are needed for design of the project, protocol development, implementation of surveys, sample collection, sample processing at laboratories, data analysis, and reporting. Expense is critical to consider in light of sustainability during a time of decreasing global funding for HIV, specifically in regions outside of sub-Saharan Africa.
- BBS are time consuming to plan and implement, as they require input from multilateral partnerships (i.e., funding agencies, CBOs, MOHs, implementing partners), time for protocol development and ethical approval, and development of a novel surveillance platform in every case, since the methodology is outside of the realm of routine national surveillance. Delays due to ethical approval can equate to higher costs for implementation. While the expenditures lead indirectly to programmatic improvement, as compartmentalized projects, BBS resemble epidemiologic research more than activities that directly strengthen routine surveillance and programming.
- The success of a BBS is greatly dependent on current political, social, and legal contexts, which can fluctuate within the survey implementation period. This is a disadvantage, as surveys may take years to implement and complete. The

contextual environment can change to such a degree that KP community support for the project decreases and individuals become hesitant to participate, as was the case for two of our BBS in the region. In one case, a KP community witnessed a surge of violence toward another KP group in the country, and this threat may have slowed participation. In another case, even when an FA indicated the presence of community support for a BBS, the perception of potential stigma and discrimination based on the changing socio-political context was a likely factor in deterring participation. Difficulties in BBS implementation in the Caribbean have ranged from reasons as intrapersonal as an increase in the number of conjunctivitis cases among KP to societal factors such as shifting of policing practices in targeting KP and increases in political violence. Changes in government over time can also result in reprioritization of domestic funding and support for BBS, especially for KP.

- As BBS behavioral data are self-reported, private, and sensitive, and social desirability bias can affect responses, whereby participants are hesitant to report their behaviors. This problem could equally affect programmatic collection of behavioral data, and BBS have the advantage of providing anonymity to participants. But longitudinal programmatic data collection provides an opportunity for KP to establish a comfort level with the surveillance program collecting data, and this does not exist for singular surveys. BBS are also subject to recall bias when participants are asked about their behaviors over long intervals.
- Despite providing population-level estimates, the representativeness of BBS are limited to the sample from which the participants come. For example, for our BBS in The Bahamas, we were unable to provide national-level population size estimates of MSM because our sampling frame did not include several islands with significant populations. If the estimates had been presumed to be nationally representative, these could have been biased.
- An ethical obligation exists to return results of biological tests (e.g., HIV, viral load) to patients and to ensure the patients are linked to care and treatment services within the routine MOH system. Especially in newly diagnosed PLHIV, this obligation is difficult to achieve while maintaining anonymity, and this can slow down the ethical approval process. In the Caribbean context, return of results is further complicated by the lack of anonymity available to any member of the community, especially KP, due to intimately connected communities with small population sizes and high levels of stigma and discrimination.

OPPORTUNITIES AND STRATEGIES TO OVERCOME CHALLENGES

Reaching Sample Size.—Specific information we have can be collected during the FA to determine the feasibility of reaching the desired sample size includes: the interconnectedness among KP networks; the willingness of participants to refer other KP to the survey; whether KP members are comfortable disclosing KP status for the purposes of the survey; and whether those who are comfortable disclosing would also be comfortable being tested for

HIV. The FA should assess the target population's perception of acceptability of the survey to inform the feasibility of reaching the sample size. Given the small population size of some of the Caribbean countries, our assessments have included KP hot-spot mapping and KP size estimation by manual counts to ensure an adequate population of potential participants is available to reach sample size goals.

Incentives.—Local contexts must be understood to determine the appropriate incentives, and without a correct understanding, a biased sample might lead to survey failure or sample size may not be reached. KP dynamics should be investigated during the FA process through focus groups and interviews with KP key informant members.

Funding.—Declining global funding for HIV/AIDS is occurring simultaneous to the recognition that BBS are urgently needed to fill data gaps in order to meet UNAIDS global HIV/AIDS targets. As donor funding decreases, MOHs may be hesitant to fund costly one-time surveys that provide high-quality data but do not necessarily impact programs directly. When BBS is not feasible, one alternative is to collect bio-behavioral information from clinic-based programmatic surveys or at sites that offer services to KP. For example, sentinel surveillance that includes enhanced routinized data collection can provide important epidemiologic information about HIV-infected and -uninfected populations, the demand for HIV services, and the ability to track KP and link them to services (Nguyen et al., 1999; Soto et al., 2007). These alternative methodologies are not a replacement for BBS; a major limitation of clinical surveillance is that population-level estimates cannot be accurately estimated from clinical data only, even if the estimates are valid for the clinical population sampled. Clinic populations may differ from overall population, and KP nondisclosure due to stigma might limit the ability to make estimates. But prevention and treatment service delivery inherent in this approach might be more palatable for MOHs than expensive surveys that don't provide services to KP, especially in regions experiencing donor fatigue and diminishing resources for HIV. MOHs in the Caribbean have been supportive of receiving technical assistance to implement sentinel surveillance as donor funding has diminished. Alternatively, if MOHs are able to routinize BBS by conducting consecutive surveys using internal staff and tools that have been developed during previous rounds of implementation, the cost of BBS could be greatly diminished compared to a one-time survey utilizing external technical partners.

Timeliness.—There are ways in which the length of time to plan and implement a BBS could be decreased. While the FA is essential to inform the survey methodology, we have combined the protocols for the FA and the BBS so that only one ethical review would be required. This reduces the time between the finalization of the FA and beginning BBS implementation. To address the issue of creation of a novel surveillance platform, which increases both cost and time, BBS can be routinized within MOH programming as part of ongoing surveillance activities so that future rounds of the survey do not bear the cost of the original, providing continuous, timely programmatic feedback through comparison of trends in data. Sentinel surveillance that leverages the existing surveillance platform and adds KP and behavioral information could gather at least some information normally collected by BBS. In all cases, we have provided post-survey BBS tool kits to the MOH and ensured

locally-hired project coordinators during BBS implementation to increase the capacity of the MOH to implement future rounds of BBS in a timely manner.

Political Environment.—It is important that donors and implementers are aware of changes in the governmental and social sensitivities surrounding KP. This is accomplished by forming and frequently convening local steering committees that include KP members. The committee can provide information about current community acceptance for the activities and whether there is likely to be changes. In one country, KP that had witnessed an increase in arrests felt more comfortable visiting the survey site in pairs. Strategies that increase participation despite a difficult political environment should be encouraged.

Self-Reporting of Sensitive Information.—To increase the willingness of BBS participants to provide sensitive information implementers could offer alternative methods of collecting data, for example, using self-interview software. We have employed audio computer-assisted self-interview (ACASI) software, which facilitates participants to respond to questions privately on a computer, aids in consistent question delivery, and increases timeliness, as data entry from paper forms is eliminated. Internet-based surveys have also been conducted within the Caribbean region (UNAIDS, 2014b). These can ensure privacy by permitting the participant to partake in the survey from a private space. Other strategies to enhance collection of accurate sensitive information are to ensure that placement of sensitive questions is not at that beginning of the survey, so that a participant can establish rapport with an interviewer before answering them, and ensuring that the terminology and language used in questions is appropriate and familiar to participants.

Nonbiased Samples.—To ensure population representativeness, it should be determined in advance which members of the population the sample will cover. For RDS, the FA should provide information about whether populations are well connected and whether individuals will recruit other groups of KP into the survey. If these connections are not strong, the study may fail to reach the desired sample size or provide incorrect estimates of the target population.

Ethical Challenges.—To maintain participant anonymity while ensuring linkage to care, solutions can be found by working with ethical review boards and HIV programming officials in the target country. This could lead to reaching a common understanding of ethical requirements and an understanding of how the proposed protocols fit into the standard programmatic practices of the MOH. In order to satisfy U.S. government ethical requirements, HIV testing results must be provided to participants in an active manner rather than relying solely on patients returning for results. To facilitate this mandate, we have utilized outreach workers to ensure test results are delivered to patients who are not able to return to the survey site to receive their results.

RECOMMENDATIONS

- Ensure partnerships with KP CBOs and KP key informants throughout the BBS process by the formation of a steering committee. Informants should be relied

upon to inform the team about acceptability of the surveillance activities within the community.

- FAs should guide the implementation of BBS, and should be relied upon to provide qualitative and contextual information to understand the KP community, its size, potential socio-political challenges, and to make decisions about appropriate survey methodology to provide unbiased population-level estimates.
- FA protocols should be combined with survey protocols to increase efficiency and improve timeliness. MOHs should be provided the tools and skills necessary to embed future rounds of BBS into their surveillance platform.
- When possible, tools that encourage safe disclosure of sensitive information and risk behaviors should be used to improve issues involving self-reporting of behaviors.
- Solutions to potential ethical challenges should be sought early during the planning phase by engaging an ethical body and the MOH to determine how to ensure participants receive timely results and are linked to quality services while their anonymity is maintained.
- Less costly and faster alternatives to BBS could be considered, such as routinized sentinel surveillance, depending on available funding, the needs of the MOH and KP groups, and relevance and feasibility of surveys. The limitations of these surveillance alternatives, such as the lack of ability to obtain population-based representative data for KP, and the role of triangulation of various data sources should also be considered as part of the iterative decision-making process for ongoing KP surveillance.

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TABLE 1.

Bio-behavioral Surveys and Timelines, Center for Disease Control and Prevention, via PEPFAR’s Caribbean Regional Program, 2012–2017

BBS component	Items within component
BBS objectives	<ul style="list-style-type: none"> Obtain population-level HIV prevalence estimates Obtain population size estimates Obtain prevalence estimates of HIV risk behaviors Determine the prevalence and correlates of HIV and other sexually transmitted infections (STIs) Assess HIV and STI testing behaviors Identify gaps in prevention and treatment that affect KP and inform the MOH through provision of recommendations for KP program planning Provide tools to the MOH to conduct future rounds of BBS
Activities undertaken at survey office	<ul style="list-style-type: none"> Screening Informed consent Questionnaire administration HIV/STI testing HIV/STI counseling Referrals to HIV/STI care Sample collection (if applicable) Provision of results (if applicable)
Questionnaire domains elicited	<ul style="list-style-type: none"> Demographic characteristics Substance use behavior Sexual history HIV knowledge and prevention behaviors Experiences and perceptions of stigma and discrimination Social media use and participation in LGBT events (to facilitate population size estimation)
Tests conducted	<ul style="list-style-type: none"> HIV Any of the following: syphilis, gonorrhea, herpes simplex virus 2, Chlamydia Hyperglycemia, hypertension, cholesterol Viral load HIV genotyping for drug resistance
Population size estimation methodologies implemented	<ul style="list-style-type: none"> Literature review Census and population size estimation (during the formative assessment) Unique object multiplier Service multiplier

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TABLE 2.

Bio-behavioral Surveys and Timelines, Center for Disease Control and Prevention, via PEPFAR's Caribbean Regional Program, 2012–2017

Country	Key Population	Methodology	Years of Data Collection
Barbados	MSM	Respondent-driven sampling	2012–2014
Trinidad and Tobago (Ministry of Health, 2016)	MSM	Respondent-driven sampling	2013–2014
Antigua and Barbuda (Ministry of Health, 2015)	SW	Respondent-driven sampling	2014
The Bahamas	MSM	Respondent-driven sampling	2014–2015
Trinidad and Tobago	SW	Respondent-driven sampling	2017–2018
Jamaica	MSM	Respondent-driven sampling	2017–2018 (ongoing)

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