



RESPONDENT-DRIVEN SAMPLING:

A Resource Guide for Steering Committee Members

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Table of Contents

Glossary	2
Introduction	3
About Steering Committees	4
What is a Steering Committee?	4
What is the Purpose of a Steering Committee?	4
What are the Responsibilities of a Steering Committee?.....	4
About Key Populations	6
What are Key Populations?	6
Why Survey Key Populations?	6
Respondent-Driven Sampling	8
What is a Formative Assessment?	8
What is Respondent-Driven Sampling?	9
Why use Respondent-Driven Sampling?	9
What are Seeds?.....	10
What is Needed for Respondent-Driven Sampling?	10
Coupon Management	11
Tracking Recruitment.....	11
Distributing Coupons.....	11
Coupon Characteristics	11
Summary	13
Additional Resources	14
Appendix	16

Glossary

Biological and Behavioral Surveillance Survey (BBSS): Data collection consisting of two elements: 1) a survey of behaviors and knowledge related to risk of acquiring the disease(s) of interest, and 2) biological testing to determine the participant’s disease status with respect to each disease.

Bridge: An individual engaging in high-risk behaviors who is also connected with the general population, thus increasing the risk of HIV transmission to a larger, lower-risk group.

Formative Assessment: A study conducted prior to the implementation of a larger research project. Its primary objective is to answer questions in order to facilitate the implementation of the main survey.

Human Immunodeficiency Virus (HIV): A virus transmitted by the transfer of bodily fluids that targets human immune cells, leading to immunodeficiency and AIDS.

Key Populations: One of various sub-groups that is at elevated risk of HIV infection or transmission because they engage in specific, known high-risk behaviors and/or are stigmatized by the general population.

Key Populations Steering Committee: Multi-sectorial advisory committee to the Ministry of Health (MOH) consisting of individuals with local content expertise in service provision and policy formulation for key populations.

Recruitment: In respondent-driven sampling, the process of providing coupons to participants and following up on coupons distributed, with the ultimate goal of identifying enough eligible survey participants to reach the stated sample size.

Respondent-driven Sampling (RDS): Chain-referral sampling that starts with a limited number of “seeds” who refer their peers. RDS is based on the theory that bias in recruitment is overcome after recruitment proceeds through a sufficiently large number of waves.

Seed: An individual who is well-connected within the networks of the surveyed community. Each seed will recruit individuals within his network to start the waves of sampling in RDS.

Introduction: About This Guide

Serving as a key population steering committee member can be both a rewarding and a fulfilling experience. Several decisions for biological and behavioral surveillance surveys (BBSS) with key populations are made through the guidance and recommendations of steering committee members, which is important for successful engagement with the community and administering activities. Your knowledge of the community and your connection to the key population is valued as we prepare for and implement the BBSS.

This guide will help you understand your role as a steering committee member and serve as a quick reference on the respondent-driven sampling method.

BBSS research is an effective method for capturing information among key populations because they link behavioral questions in surveys to biological testing to provide greater explanatory power than either method alone. Information gathered from the BBSS identifies risks, practices and the prevalence of HIV infection and other STIs among populations at greatest risk.

For this reason, it is important to appropriately communicate the technique, or methodology, we will use for gathering information through the BBSS. Understanding the respondent-driven sampling (RDS) methodology will be our main focus in this guide. Explaining RDS to the target population and other stakeholders in a manner which they will comprehend can be challenging. However, this guide will help you understand the RDS methodology and equip you with the language you need to communicate steps appropriately. Additionally, you will get a better sense of your role as a steering committee member and the responsibilities you will be tasked with during your tenure.

As you read through this guide, consider how the information it contains can help foster your relationship and strengthen your credibility with the key population of interest. Providing a detailed description of RDS methods is beyond the scope of this guide, however additional resources can be found at the end of the guide.

About Steering Committees

What is a Steering Committee?

A steering committee is an advisory body to the Ministry of Health (MOH) and consists of individuals with local expertise in service provision and policy formulation for key populations. Ideally, a steering committee is made up of six to ten members who have positive working relationships with the key population of interest and experience working in the HIV/AIDS field in their country.

What is the Purpose of a Steering Committee?

Your country is home to local non-governmental organizations and international entities with expertise in surveillance, HIV/AIDS, and key populations. A shared vision is required to implement an effective surveillance study. The purpose of the steering committee is to bring together these experts to effectively guide and actively contribute to the goals of BBSS among key populations.

What are the Responsibilities of a Steering Committee?

The steering committee is responsible for several important tasks that require regular attendance at meetings and active participation outside of meetings:

- Advocate for BBSS activity and method to appropriate stakeholders
- Ensure that the surveillance activity meets data needs
- Facilitate connections between MOH and key populations
- Advise study team on study logistics
- Assist the MOH to troubleshoot issues as they arise
- Advise on data interpretation and conclusions
- Maximize data dissemination and use.

When the surveillance activity is in the implementation phase, you may be asked to meet monthly to discuss issues as they arise. The need for meetings may become less frequent as the committee addresses implementation hurdles. Note that although meetings may be less frequent, meeting every other month is recommended. It is important that you continue to engage in the activities of the steering committee for the duration of the surveillance activity. You may also receive communication by email asking for your input on the activity.

A steering committee member is active in contributing to the goals of the project and seeks to connect with the key population and other stakeholders to communicate about the surveillance activity.

About Key Populations

What are Key Populations?

Certain populations are at a higher risk for transmitting HIV to others and/or contracting HIV because of behaviors they engage in. Internationally, these populations are referred to as key populations, and are typically defined as commercial sex workers (CSWs), men who have sex with men (MSM) and people who inject drugs (PWID). These groups engage in behaviors that are known to increase risk of HIV transmission, include the following:

- Having sex without a condom (unprotected sex)
- Having unprotected sex with people who are HIV positive
- Having unprotected sex with multiple partners, especially in a short time-period
- Having unprotected sex where there is exposure to blood from torn tissue (i.e., without sufficient lubricant)
- Injecting drugs with shared needles or sharing other drug paraphernalia.

Why Survey Key Populations?

Due to participation in higher-risk behaviors, key populations often play a role in establishing, advancing, or sustaining an HIV epidemic. Key populations may be the first to be infected with HIV in a new epidemic, or are infected at higher rates than the general population. Key populations may serve as a bridge, transmitting HIV to other segments of the population.

Thus, understanding the state and trends of the epidemic among key populations helps to design needs-based HIV prevention, education, and treatment and care programs to reach those at greatest need. Effective and targeted programs will ultimately lessen the national impact of HIV.

The greatest benefit of surveillance among key populations is in the wealth of information gained. However, this data must be used to implement change. As a steering committee member, you are asked to assist the MOH with data interpretation and dissemination to ensure results are shared appropriately and information is used to best address the epidemic in your country.

Findings from a BBSS may help you to identify early warning of a changing epidemic, monitor the epidemic among a key population, or assess the impact of existing public health programs.

Respondent-Driven Sampling

What is a Formative Assessment?

Before deciding whether the RDS methodology is suitable, an assessment is conducted using qualitative methods to ask questions of persons knowledgeable about the key population:

- Are they well-networked?
- Is everyone in the community connected, or are there closed groups?
- Will participants be willing to recruit their peers into the study?
- Where should study sites be located to facilitate access?
- What biological tests should be offered?
- How can trust with the key population be gained for this activity?

The formative assessment is typically the first step in planning a BBSS. This pre-survey activity defines the parameters of the survey by identifying logistics, approaches and methods that are acceptable to the key population.

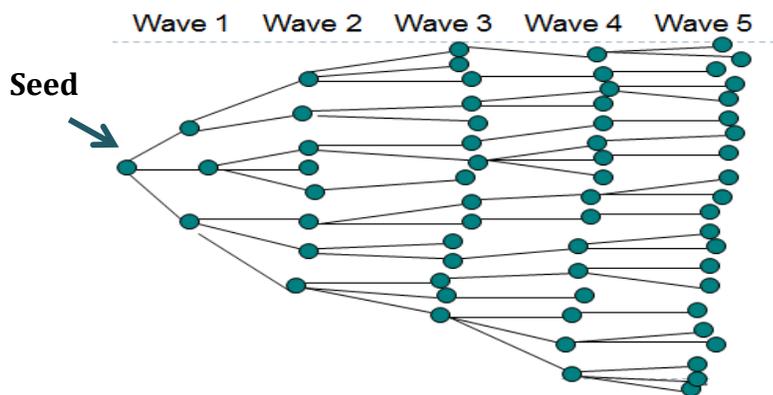
Additional benefits of a formative assessment are:

- Garnering community support
- Identifying seeds for the BBSS
- Learn about the population
- Gain input on logistics for survey implementation.

What is Respondent-Driven Sampling?

In respondent-driven sampling, non-randomly selected persons recruit a set number of peers to participate in the study. Their recruits then recruit further “waves” of participants. RDS can be thought of as a modified snowball sample, where the number of people that each person can recruit is limited.

Figure 1. RDS Recruitment Chain¹



Why use Respondent-Driven Sampling?

Gathering information about key populations can be complicated by stigma and local laws. This can cause populations to be “hidden” and difficult to access via traditional surveillance methods. To assist in reaching the “hidden populations,” sampling methodologies have been developed that help to increase access to populations while maintaining a scientific basis that allows results to be generalized. RDS is one of these methods. RDS was developed in 1997 to study injection drug users and is based on the assumption that peers are best at recruiting other members of a “hidden population.” RDS is used around the world because of its effectiveness in reaching hidden populations while maintaining scientific sampling methods.

¹¹ UCSF and CDC. (2010). *Introduction to HIV, AIDS and Sexually Transmitted Infection Surveillance. Surveillance of Most-at-Risk Populations*. Retrieved from <http://globalhealthsciences.ucsf.edu/prevention-public-health-group/global-strategic-information-gsi/surveillance/surveillance-of-most-at>

What are Seeds?



RDS recruitment begins with seeds. Seeds are participants who are well known and respected members of the key population. They may be referred to the study by steering committee members, or by other means. Seeds should have a sincere interest in accomplishing study goals and be capable of gaining buy-in from their peers. Seeds are provided with an explanation of the study and are given a limited number of coupons to recruit participants.

RDS limits the number of individuals a participant can recruit. Most studies begin with six to twelve seeds. Seeds are not selected randomly, but are chosen to reflect the diversity of traits in the population so the final sample reflects differences thought to exist in the population, based on the findings of the formative assessment. Seeds are interviewed and receive an incentive for participating. They are then trained to recruit peers who in turn recruit their own peers. Seeds receive an additional incentive for each peer they recruit that enrolls.

Limiting the number of coupons each participant receives allows for longer referral chains, which allows the sample to diversify from the seeds that began the study.

RDS is a favorable sampling method because it maintains participant privacy, is capable of reaching less visible groups, and it generally requires less logistical and financial investment.

What is Needed for Respondent-Driven Sampling?

In order for RDS to succeed as a sampling method, four elements must exist:

1. Ability to document who recruited whom via tracking peer recruitment
2. Recruiter and recruit must know one another
3. Ration recruitment so a few cannot do all the recruiting
4. Must ask participants about personal network sizes.

Coupon Management

Tracking Recruitment

Coupons are the means of recruitment in RDS. When a participant recruits their peer to participate in the survey, he/she will give the recruited individual a coupon. Coupons identify individuals as a valid recruit and are required for project participation. Study coupons have a unique ID number, which allows study staff to link the recruited individual to the person who recruited him/her. This linkage is necessary for RDS data analysis.

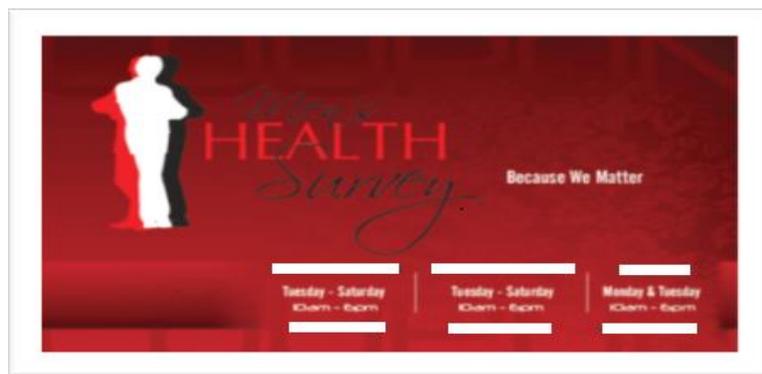
Distributing Coupons

Three to five coupons are usually given to seeds for recruitment. Choose the minimum number of coupons that will allow recruitment to progress, as it reduces biases. Having fewer coupons usually leads to more “waves” of participants and greater sample diversity. Too few coupons may not provide enough incentive to recruit, however, so there must be a balance in the number of coupons must be found.

Coupon Characteristics

The coupon should contain sufficient information for participants to be able to contact the study. Figures 2 and 3 illustrate the elements of a sample coupon.

Figure 2. Front of Coupon



The front of the coupon usually includes:

1. Coupon number
2. Name of the survey
3. Phone numbers to call for information and to schedule an appointment
4. Days and hours of operations
5. Location(s) of survey sites
6. Survey logo
7. Mention of the possibility of an incentive.

Figure 3. Back of Coupon



The image shows the back of a coupon for the "Men's Health Survey". On the left, there is a form with the following fields: "APPOINTMENT DATE:", "APPOINTMENT TIME:", "COUPON NOT ACTIVE BEFORE:", and "COUPON EXPIRES:". To the right of the form is a red "APPOINTMENT CARD" with a silhouette of a man and the text "Men's Health Survey". Below the appointment card, there are three columns of text indicating operating hours: "Tuesday - Saturday 10am - 6pm", "Tuesday - Saturday 10am - 6pm", and "Monday & Tuesday 10am - 6pm".

The back of the coupon usually includes:

1. Name of the survey
2. Space for survey staff to record operations and tracking information
3. Space for participant to record date/time of appointment
4. An activation and expiration date.

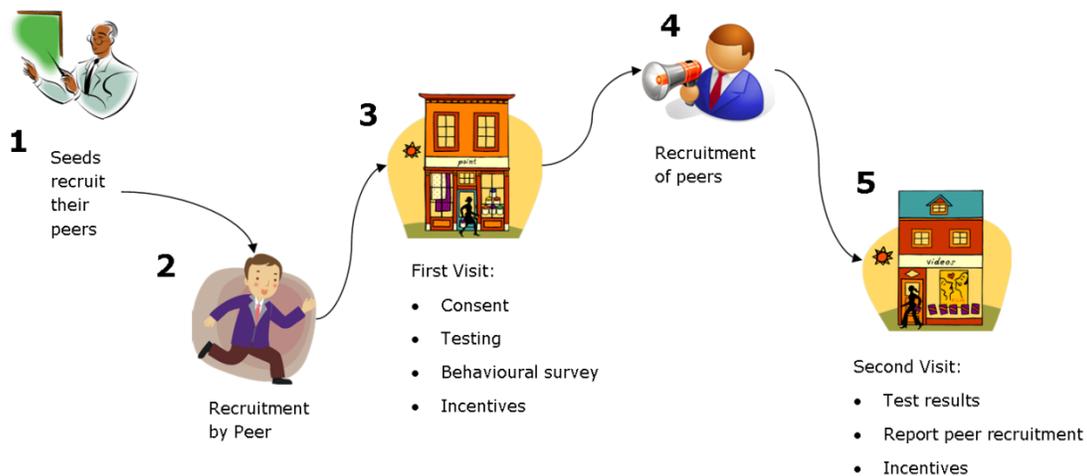
Other information may be included on the coupon as you see fit.

Summary

Plans to implement a BBSS with a key population require the skills of local experts throughout the process. To meet this need, MOH may convene an advisory committee of individuals from the public and private sector to assist with this process. Steering committee members are selected based on knowledge, experience and history of working with the key population.

BBSSs ask participants about practices that influence risk of HIV transmission, and offer screening for HIV and other diseases. Potential participants may be recruited using RDS, a method where a small number of “seeds” are selected by the study team and are given a limited number of coupons to recruit peers in their network to participate. This allows for greater coverage because respondents are reached through their social networks. You will find additional advantages as well as challenges to implementing RDS in the additional resources provided. Figure 4 demonstrates the steps used in RDS.

Figure 4. RDS Implementation Steps



As you see the data from the BBSS, you can use your role on the steering committee to advocate for improved services for the targeted key population.

Steering committee members are essential to the success of the BBSS because they connect the study team to the group they intend to serve.

Additional Resources

1. CDC Morbidity and Mortality Weekly Report on the National HIV Behavioral Survey conducted with injecting drug users in the U.S.
2. Decker, M. R., & Ramachandran, D. (2012). Respondent-driven sampling: finding the invisible. [Presentation]. Retrieved from <http://www.jhsph.edu/departments/population-family-and-reproductive-health/docs/seminar-2012-10-31-rds.pdf>
3. Heckathorn, D. D. (1997). Respondent-driven sampling: A new approach to the study of hidden populations. *Social Problems*, 44(2), 174-199. Retrieved from <http://www.respondentdrivensampling.org/reports/RDS1.pdf>
4. Heckathorn, D. D. (2002). Respondent-driven sampling II: Deriving valid population estimates from chain-referral samples of hidden populations. *Social Problems*, 49(1), 11-34. Retrieved from <http://www.respondentdrivensampling.org/reports/RDS2.pdf>
5. Johnston, L. G., & Sabin, K. (2010). Sampling hard-to-reach populations with respondent-driven sampling. *Methodological Innovations Online*, 5(2), 38-48. doi: 10.4256/mio.2010.0017
6. Johnston, L., Malekinejad, M., Kendall, C., Iuppa, I. M., & Rutherford, G. W. (2008). Implementation challenges to using respondent-driven sampling methodology for HIV biological and behavioral surveillance: Field experiences in international settings. *AIDS and Behavior*, 12(suppl. 4), S131-141. doi: 10.1007/s10461-008-9413-1
7. Magnani, R., Sabin, K., Saidel, T., & Heckathorn, D. (2005). Review of sampling hard-to-reach and hidden population for HIV surveillance. *AIDS*, 19(suppl. 2), S67-S72. Retrieved from http://respondentdrivensampling.org/reports/AIDS_2005.pdf
8. Malekinejad, M., Johnston, L. G., Kendall, C., Kerr, L. R., Rifkin, M. R., & Rutherford, G. W. (2008). Using respondent-driven sampling methodology for HIV biological and behavioral surveillance in international settings: A systematic review. *AIDS and Behavior*, 12(Suppl 4), S104-S130. doi: 10.1007/s10461-008-9421

9. Montealegre, J., Johnston, L. G., Murrill, C., & Monterroso, E. (2013). Respondent-driven sampling for HIV biological and behavioral surveillance in Latin America and the Caribbean. *AIDS and Behavior*, 17(7), 2313-2340. doi: 10.1007/s10461-013-0466-4
10. White, R. G., Lansky, A., Goel, S., Wilson, D., Hladik, W., Hakim, A., & Frost, S. D. (2012). Respondent-driven sampling - where we are and where should we be going? *Sexually Transmitted Infections*, 88(6), 397-399. doi: 10.1136/sextrans-2012-050703.

Appendix



Sample Steering Committee Talking Points

Gatekeepers: (house leaders, event promoters, etc.)

1. **Question:** How will this Survey affect the MSM population nationally?

Answer: The survey will be beneficial to the MSM population in our country because the survey aims to facilitate HIV prevention activities. This in turn will allow the MoH to have a better understanding of the behaviours and health needs of the MSM population and provide readily available information so that applicable prevention/ outreach programs and policies can be put in place to further assist the MSM community. The results from this survey will positively impact the community as current strengths and weaknesses in services will be identified.

2. **Question:** How will the survey affect the confidentiality of gatekeepers and our MSM networks?

Answer: One of our top priorities is providing and maintaining a veil of confidentiality for all gatekeepers and participants. We understand the vulnerability you are undertaking by trusting us, and it is our mission not to abuse or misuse that trust for any purpose. Study staff will be required to maintain confidentiality or risk termination. Our site location will be discreet with no visible signs or logos that will draw attention to the location. We will also encourage eligible gatekeepers who receive a coupon to take part in the study that way you can share your experience with potential participants.

3. **Question:** How will gatekeepers benefit from assisting in this survey?

Answer: You will have the satisfaction of giving back to the MSM population in [country], which will increase the level of trust they have in you. Not to mention the personal satisfaction of knowing that you will be helping the MoH to gather the necessary data, which will help us to better serve the community.

4. **Question:** What must one do to be eligible to participate in the survey?

Answer: If a participant receives a coupon to participate, he will be eligible for the study if he:

- Currently is of the male sex although not required to identify as a man
- Have engaged in oral and/or anal sex with another male
- Are 18 years of age or older
- Live in the [country] for past 12 months

Stakeholders (NGOs, FBOs and MSM specific Organizations and other advocacy groups)

1. **Question:** What is the purpose of this survey?

Answer: The purpose of the survey is to provide the Ministry of Health and other organisations in [country] with up-to-date information to help improve HIV prevention throughout the country. By having this information readily available, we hope to encourage an attitude of change, prevention, education and awareness.

2. **Question:** What makes this study different from all the rest?

Answer: This study is different because it is being conducted by the MoH and their technical assistance partners, NASTAD. The information gathered will help the MoH to serve the MSM population in [country]. It will allow the MoH to improve healthcare access, policies, and outreach efforts geared towards this community as we will know more about their behaviours.

3. **Question:** What are you going to do with the information you collect?

Answer: Presently, behavioural information about key population, such as the MSM population is not available to the MoH, the MSM community and other stakeholders. There has been a lack of information and programs aimed directly at addressing the needs of key population in [country]. With the information we gather we will be able to identify the needs that arise and plan for prevention interventions.

4. **Question:** How are you going to recruit participants for this survey?

Answer: We are going to utilise Respondent Driven Sampling, a scientific method to recruit participants for the study. Individuals known as seeds, who are well respected in the MSM community and referred by members of the steering committee and other key stakeholders, will be given coupons which they will pass on to the people in their networks. These individuals in turn refer those they know and so on. People cannot volunteer for the study.

Support Services: (Organisations targeting MSM needs and Physicians serving MSM)

1. **Question:** What is the Men's Health Survey?

Answer: The Men's Health Survey is part of a national health survey executed by the Ministry of Health and their technical assistance partner, NASTAD. We are surveying different populations to learn about HIV prevalence, sexual and drug use trends, and use of local HIV prevention programs. The main objective of the survey is to provide the Ministry of Health and other organisations in [country] with up-to-date information to help improve HIV prevention throughout the country.

2. **Question:** How will we be able to access patient's lab results?

Answer: You will not be able to access lab results for the participants as this is confidential. Each participant will be informed of their test results and given a list of providers that can offer them care. Should the patient select you as a provider for care or service, they will have their results with them for you to review if they choose to come for an appointment.

3. **Question:** How many participants are there, and how many should I look forward to providing care for?

Answer: If the participant presents positive for HIV or another STI and if the screening show elevated levels which may indicate a chronic disease, we will recommend various treatment facilities if the participant do not have a primary care provider. There will be no disruption to your current flow of patients. Our recruitment target is 350 participants.

4. **Question:** If a participant chooses my facility for treatment for an STI, will the Men's Health Survey cover the cost?

Answer: No. The MHS do not cover expenses for treatment. The participant will be responsible for the costs.

Seeds and Participants:

1. **Question:** When I come in for the Survey, can my friend and I do it together?

Answer: If you and your friend have a coupon and given there is an open appointment, you can come to the site together. However you will not be able to take the survey together as the questions are designed for individual responses. Our desire is to track responses individually in a private and confidential manner.

2. **Question:** What's in it for me? Why should I take part in this survey?

Answer: Information gained from this study will help the Ministry of Health know more about HIV, STIs transmission in the MSM community. This information will be used to improve health programs and to develop new ways of helping others prevent disease and promote positive health. Free screening for diabetes, cholesterol and hypertension and free testing for HIV and STI will be offered. Additionally, if your HIV test or STI test results are positive, you will be counselled about ways to prevent the spread of infection. You will also be offered information about available medical care for any infections or if screening shows you may have a chronic disease.

3. **Question:** Will I be compensated for my time?

Answer: We appreciate the time and effort you will spend in order to participate. You will be paid for the time you spend taking part in the study in the form of gift cards or phone cards. You will not receive cash. For completion of the survey, you will get a gift or phone card. If you take part in all the health screens, you will get an additional gift or phone card. You may also get an additional gift or phone card of lesser value for up to three people whom you send to us who enroll in the study. In order to receive an additional phone or gift card for sending your peers, they have to be eligible to participate in the study. If the people you send are not eligible for participation or unable to enroll, you will not receive an additional phone or gift card for that individual.

4. **Question:** Why did you choose a “Men’s Health Survey”, why not just a general Health Survey?

Answer: Generally speaking, men don't particularly view medical care as a priority, granted there are exceptions. MoH has limited information on the key populations in [country] and are hopeful that this survey will aid in gaining a better understanding of the behaviours of men in [country]. The Survey will gather biological and behavioural information based primarily on HIV and STIs among the MSM community. Once we have the information we need for the BBSS we can implement programs and services to make them more comfortable to seek medical care and other help within the community.

5. **Questions:** What if the results come back that I have HIV or an STI will you treat me?

Answers: Unfortunately, we do not have a physician on staff to provide follow-up care for any positive test result and we do cover the cost of your treatment. However, we do have a list of treatment facilities in [country] which includes physician who are MSM-friendly we can refer you to for care. We can also refer you to NGOs in the community that would be willing to assist you with selecting a treatment facility and provide education and awareness. NGOs such as XX, XX, XX and other stakeholders are MSM-friendly and can assist you to navigate through this process

General Questions:

1. **Question:** What is the duration of this Survey?

Answer: The duration of the survey is six to twelve months.

2. **Question:** How will you know if participants answer the questions honestly and how do you know the data will be viable?

Answer: There is no way of guaranteeing that participants will provide truthful responses. However, we will do the best we can to let all participants know that answering the questions honestly is of the highest importance. One of the ways we will try to do this is by ensuring confidentiality in handling all information. Also, we believe that providing options to choose between answering questions via ACASI software (self-administered) or the CAPI option (computer assisted interviewer administered) will facilitate participants comfort and ease to respond honestly.